An exploratory study of patients' and physiotherapists' perceptions and preferences when making decisions and sharing information about managing low back pain in Saudi Arabia

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Abstract

Background: Involving patients in making decisions about the management of health conditions enables clinicians (including physiotherapists) and patients to deliberate about options and share information about the clinical situation; this may help to improve patients' adherence and self-control over their illnesses. Low back pain (LBP) is a common and debilitating problem often managed by physiotherapists. The preferences of these patients and physiotherapists for involvement in decision making and, more specifically, those of patients and physiotherapists in Arabian cultures such as Saudi Arabia is largely unknown.

Aim: to explore the perceptions and preferences of physiotherapists and patients with LBP for patient involvement in decision making and information provision.

Research Design: This exploratory study was conducted in Saudi Arabia using a mixed methods approach, employing structured questionnaires followed by in-depth focus groups.

Methods: Phase 1: A cross-sectional study was conducted with patients with LBP (n=296) and physiotherapists (n=93) using self-completion questionnaires developed for this study to examine the above aim. **Phase 2:** Ten focus group studies were carried out with participants to examine the reasons for their preferences. **Analysis**: Descriptive and inferential statistics were conducted to examine quantitative data; verbal transcripts were analysed using framework analysis. **Results:** Most patients preferred to adopt a more passive role in decision making within the clinical setting, but wished to share decisions about aspects occurring elsewhere (e.g., routine daily activities and home management programs). Patients' demographic and LBP characteristics were generally significantly associated with their preferences ($p < 0.001$-0.05). Physiotherapists were generally paternalistic in their approach to decision making. The in-depth information derived from the focus groups confirmed the questionnaire findings and provided some reasons for participant's preferences. **Conclusion**: These findings provide information on which to base future studies to investigate the possible effect of preferences on treatment outcomes and the long term 'self-management' of LBP.

Dedication

I dedicate this thesis to my beloved mom

Acknowledgment

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Chapter one

Introduction to the thesis

1.1 Introduction

The current thesis examines preferences of physiotherapists and patients with low back pain for patient involvement in decision making and information provision, within physiotherapy context, in Saudi Arabia.

This introductory chapter sets the scene for the current research and falls into three sections:

1.1 introduces the cultural and healthcare setting in Saudi Arabia; **1.2** addresses the motivation and rationale for the study, its design and aims; and **1.3** outlines the contents of the thesis.

1.2 The Saudi cultural and healthcare setting

1.2.1 Cultural background

Saudi Arabia is at the heart of the Arab Islamic world and the site of the two holy cities of Islam. It is one of the richest countries in the Middle East and the largest producer of oil in the world. In 1902, the Al-Saud family captured Riyadh (now the capital city) under the leadership of King AbdulAziz Al-Saud, who unified the land under the name of Saudi Arabia in 1930. The country was then divided into thirteen administrative areas, as shown in Figure 1.1. The majority of the Saudi population lives in Makkah (26%), Riyadh (24%) and the Eastern province (15%) (Central Department of Statistics and Information, 2011), whose respective capital cities are Jeddah, Riyadh and Dammam.

The cultural background of the population is diverse, although most Saudi citizens are Arabs and all are Muslims. The variations are generally related to the differences in lifestyle between those whose families or earlier generations traditionally lived in the desert and those with long term roots in the cities. It is also commonly suggested that

people from the west of the Kingdom are more open to other cultures, having become used to mixing with millions of pilgrims and visitors to the two Holy Mosques.

In a very recent report, the Central Department of National Statistics and Information (2011) states that the Saudi population was estimated to be over 27 million in 2010, having grown by 3.2% annually between 2004 and 2010. The same report indicates that Saudi citizens comprised about 68.9 % of the total population, that 67.1% were under 30 years old, whereas only 5.2% were aged above 60 years, and that the ratio of males to females was 50.2:49.8% (Mobaraki and Soderfeldt, 2010).

Figure 1.1: The thirteen administrative and geographical areas of Saudi Arabia

Since 1930, Saudi Arabia has undergone fundamental and continuous development in its industry, economy, health care, education, infrastructure and community. These developments have led to changes in the social life of the Saudi population; however, Saudi culture remains family oriented and strongly rooted in Islam as a religion and way of life.

In Islam, faith is not split from life and life is guided by faith. All Muslims are equal, whatever their colour, race or position. For complete faith, Muslims must believe in Allah (God), His angels, His sent books, His messengers, the last day and fate, whether good or bad. This belief in fate helps Muslims to accept illness. Muslims believe that they will be rewarded if they accept their fate. However, accepting illness does not mean not seeking treatment, since this is regarded in Islam as a self-responsibility that

aims to preserve bodily and psychological wellbeing (Nabolsi and Carson, 2011). Hence, individuals and groups are responsible for their health and are required to cooperate to maintain good health as appropriate.

Ethical considerations in Islam encourage collaborative approaches within society and support full independence in making decisions about someone's health. In principle, Islam shapes this with the requirement not to harm intentionally anyone's body, spirit or possessions; it is narrated by Ibn Majah (824) that the prophet, peace be upon him, said: "There should be neither harming nor reciprocating harm". On the contrary, according to Islamic principles, people should collaborate to achieve moral good and avoid unethical deeds; this is in the meaning of what Allah said in the Holy Qur'an, translated as: "Cooperate in righteousness and piety, but do not cooperate in sin and aggression" (Holy Qur'an: chapter 5, verse 2) and "those who have responded to their Lord and established prayer and whose affair is (determined by) consultation among themselves" (Holy Qur'an: chapter 42, verse 38).

1.2.2 Health care in Saudi Arabia

The Saudi healthcare system has been ranked 26th among 190 by the World Health Organization (The world health report, 2000). As the primary healthcare provider in Saudi Arabia, the Ministry of Health (MOH) provides preventive, curative and rehabilitative health services for the Saudi population (Walston et al., 2008). The high demands on the MOH led the government to increase healthcare spending to 78 billion Saudi riyals in 2012 (Ministry of Finance, 2012). The principle mission of the Ministry is to provide the best possible healthcare services in every region of the Kingdom and at all levels: primary, secondary and tertiary (Almalki et al., 2011). The MOH runs five medical cities (involve hospitals and health centres), 244 hospitals and 2086 primary care centres throughout the Kingdom, affording free access to all Saudi citizens and an average of five million pilgrims to the Holy Mosques (Ministry of Helath, 2012, Walston et al., 2008). However, other governmental agencies also provide healthcare services to Saudi citizens and their facilities are often regarded as maintaining higher healthcare standards; these bodies include the Ministry of Defence, the Ministry of the Interior, the National Guard and the Ministry of Higher Education

(via university teaching hospitals). In addition, the private healthcare sector has expanded from 18 hospitals in 1971 to 127 in 2010 (Walston et al., 2008, Ministry of Helath, 2012), providing health care to Saudis and non-Saudis under the authority of the MOH. Saudi and non-Saudi patients usually have access to all of these types of hospitals. In order to ensure high quality in the services offered by all healthcare providers in the Kingdom, the Saudi Commission for Health Specialties (SCHS) was established in 1982, as an independent governmental agency, to supervise and evaluate the quality of performance of all health professionals working in the various healthcare institutions.

Because of the variations among these organizations, in terms of governance and of policy, it has proved difficult to apply consistent regulation of working practice across the Saudi healthcare system, and this diversity may influence the clinician-patient association. Although the MOH emphasizes patients as its priority, it is unclear what regulations guide clinical interactions, the emphasis on patient involvement in their health care is in its infancy, and it is unknown whether any of these institutions have policies regarding patient involvement in decision making and information provision.

1.2.3 The physiotherapy profession in Saudi Arabia

The first students graduated with bachelor degrees in physiotherapy in 1980 from King Saud University, Riyadh. No statistics appear to have been published on the numbers of physiotherapy graduates, but the number of Saudi universities providing education has increased from eight to 32 over the last 15 years. In addition to nationally trained staff, the health care system in Saudi Arabia employed considerable numbers of internationally trained practitioners, though precise numbers are unknown.

The Saudi Physical Therapy Association was established in 1992 in Riyadh, by a number of Saudi and non-Saudi physiotherapists as the professional and scientific body for the profession in Saudi Arabia in 2001. It has since expanded to cover the whole Kingdom and has become a member of the World Confederation for Physical Therapy (2003) and of the Arab Confederation for Physical Therapy (2004). The number of physiotherapists registered by the Association has increased from 181 in 2002-2004 to

783 in 2011. This number does not reflect the total number of physiotherapists working in Saudi Arabia. The Saudi Physical Therapy Association aims to help physiotherapist to build their professional knowledge and skills. It also works to support the Saudi community by increasing the awareness of common musculoskeletal dysfunctions such as low back pain, by means of brochures, public awareness days (limited to Riyadh city) and respond to questions via its website.

There is no national database collecting details of the number of physiotherapy departments across these various facilities or the total number of working physiotherapists. However, hospitals with larger bed capacities will often have large outpatient physiotherapy departments, employing more than ten therapists. In recent years, a very small number of private physiotherapy clinics also provide care outside the hospital system.

The physiotherapy profession in Saudi Arabia faces a number of challenges. First, the MOH policy that indicates the professional autonomy of physiotherapists is not clear enough to differentiate physiotherapy as a health profession from the disciplines of physical medicine or rehabilitative medicine; secondly, it is unknown what health care areas are actually covered by physiotherapists and finally, the Saudi public has a stereotyped image of the physiotherapist as a masseur/masseuse rather than a qualified practitioners. Personal experience suggests that physiotherapists can therefore feel under professional 'threat' in terms of their autonomy and professional status.

1.3 Rationale for the study, motivation, research design and aims

International health policy increasingly promotes patient involvement in decision making in clinical settings (Robinson and Thomson, 2001, Légaré et al., 2009). In Saudi Arabia, such involvement has not yet been standardized as part of the national health policy, partly because of the way in which health services across the Kingdom are provided by various governmental and non-governmental agencies, each enacting its own health policy.

1.3.1 Rationale for examining preferences for patient involvement in decision making during physiotherapy for LBP

The importance of patient involvement in decision making has been increasingly acknowledged by healthcare staff and researchers in recent years, and it has been suggested that it can improve treatment outcomes, facilitate collaborative clinical associations between patients and clinicians and assist in the implementation of self-management interventions by encouraging a more active role for patients in clinical settings. It is potentially key to the practice of all health care workers, including physiotherapists.

Physiotherapy plays a central role in reducing or preventing pain and disability across a wide number of conditions, one of which is non-specific low back pain (LBP) (Cooper et al., 2008). The incidence of this is high internationally and in Saudi Arabia, and the time devoted to its management is considerable. Despite this, the uncertainty around causes of LBP is compounded by ambiguity in managing the condition (Moffett et al., 1999), and therefore managing LBP remains challenging for both patients and physiotherapists. Physiotherapy management approaches can involve either active or passive frameworks (Daykin and Richardson, 2004, Moffett et al., 1999). In the former, patients may be encouraged to cope actively with their pain using self-management approaches, whereas in passive approaches they may become more dependent on 'treatment' from their physiotherapists. In addition, negative perceptions and expectations of LBP have been reported to influence patient's beliefs about recovery (Foster et al., 2008).

Choices and decisions about management have to be made, and it is currently unknown how patients and physiotherapists discuss and exchange information about the care they receive and whether either consider (or wish to consider) the preferences of the patient in decision making before or during physiotherapy sessions. The negative perceptions and expectations of LBP add further complexity to the decision making process and appropriate and acceptable information provision when managing LBP within physiotherapy context.

While no studies have been identified that directly examine the role of health beliefs, perceptions and expectations to patient participation in decision making in people with LBP, a number of studies have looked at related areas and provide some indications of preferences in making clinical decisions. The majority of these studies have been conducted in western countries and involved small samples, and no similar studies have been reported in Arab cultural settings, including Saudi Arabia. A systematic review in 2004 of twenty studies addressing the association between patients' expectations and satisfaction with all types of treatment for LBP indicated that patients usually seek to share information with their care providers, expect advice on managing their LBP and want to have confidence in their clinicians during clinical communication (Verbeek et al., 2004). Two subsequent studies which report patient expectations of care and are set in the UK, suggest that patients with LBP expect the physiotherapist to communicate efficiently with them, individualize their treatment plans, provide them with information, give clear advice about self-management and support them throughout the treatment and follow-up periods (Liddle et al., 2007, Cooper et al., 2008). To achieve these ends, good information exchange appears necessary, although the studies provide no indication of preferences about the level or type of information.

These expectations suggest that patient involvement or participation in decision making may benefit the individualizing of treatment approaches, and patient centred care has become a key policy driver in many countries. A small UK-based interview study in 2008 with 25 patients, mostly female, attempted to define 'patient-centeredness' within the physiotherapy context. Results were categorized into six main domains: communication, individualizing care, participating in decision making, information sharing, trust in the physiotherapist and organization of treatment sessions (Cooper et al., 2008). More recently, an Australian study employing focus groups (Slade et al., 2009) investigated patients' experiences of physiotherapy for LBP. Participants (n=18) reported a need to be heard and understood by their care-providers through effective clinical communication; they were highly motivated to gain information about their back problems and displayed a strong desire to be engaged in some form of collaborative therapeutic approach (Slade et al., 2009). While both

studies show that some patients are concerned about information giving and decision making, these views are again limited to western societies and in the case of the latter study to college employees and undergraduate students.

While the above studies provide an indication of patients' wishes – and possibly preferences in a general sense – they are limited in their scope. Their main advantage is to open up a new direction when treating patients with LBP, suggesting a level of willingness on the part of patients to be actively involved and underlining the need to investigate treatment decisions in light of patient participation in decision making and information provision. There are many limitations due to the small number of participants in these studies as well as their taking place in western societies, both of which limit their generalizability. Only one (Cooper et al, 2008) was conducted in a physiotherapy context, and patients' views were obtained mainly when investigating related areas such as expectations, satisfaction and patient-centeredness.

While patients views are a key aspect of this approach, it is essential that the therapists' views are also considered; no studies have been identified that examined physiotherapists' expectations when managing patients with LBP, rather than perceptions of pain beliefs and back pain management.

The study undertaken and reported in this thesis is important as it addresses the issues discusses in an Arabic content in Saudi Arabia. While the approach taken in this context is unknown, general observation suggests that physiotherapists, particularly in Saudi Arabia, tend to adopt a paternalistic approach to decision making about care, assuming that it is they who should make the key management decisions, though person experience suggests that some patients may wish to be involved. Very little is known about patient participation in physiotherapy decision making and information provision, including that related to LBP and preferences of patients and physiotherapists; especially in Saudi Arabia.

Therefore, the study reported here aims to further our understanding of the patient-physiotherapist clinical interaction when decisions are made about managing non-specific low back pain (LBP). It provides new evidence about the perceptions and preferences of physiotherapists and patients with LBP for patient participation in

decision making and information provision. Since the existing studies about LBP as well as patient involvement in decision making and information provision were conducted in western countries whose culture and health systems are different from those of Saudi Arabia, the transferability of their findings to clinical practice in Saudi Arabia may require further investigation. The overall aim of the current research was to examine similarities and differences between physiotherapists and patients with non-specific LBP regarding their preferences for patient participation in decision making and information provision within the physiotherapy context, in Saudi Arabia.

1.3.2 Motivation for the study

My motivation for this research lay in my professional experience and clinical observations. Although I used to ask patients to state their expectations of physiotherapy, there was a day when I found myself unable to realize what a patient wanted to achieve. A patient attended the outpatient services of the physiotherapy department where I worked and asked me for a particular type of treatment for her back and shoulder pain. My immediate response was that I, the physiotherapist, should choose the appropriate treatment and not the patient. I suggested that the patient might like to let me know what goals she wanted to achieve from her treatment, but no more than this. I was concerned by my reaction, as I felt that it was her right as a patient to express her needs for a particular type of treatment. However, at that stage I did not understand what this entailed. I wondered what the key issue was: was it patient satisfaction, patient expectations or clinical communication? I searched the literature for a couple of weeks and each paper led me to another. I found myself reading about what was referred to as 'patient preferences' then 'shared decision making'. I searched a number of papers in physiotherapy and found limited information about this approach to decision making.

Hence, I found myself strongly motivated to research this topic, so I started to put together initial thoughts about clinical decision making, preferences in relation to clinical decision making, factors influencing patient preferences for participation in decision making and the role of information in these preferences; these initial thoughts were illustrated in figures (see Appendix 1.1). These thoughts were further

expanded, refined and adjusted at the beginning of my PhD course as I became increasingly interested in this topic. I also thought about bringing the preferences of patients and physiotherapists together in order to set the scene for patient participation in physiotherapy decision making.

1.3.3 Research questions

Research questions were based on a review of the relevant literature examining preferences for patient involvement in decision making and information provision, with particular reference to physiotherapy, the management of non-specific LBP and reports from non-western settings such as Saudi Arabia. The research questions addressed are the following:

- Do physiotherapists and patients with non-specific low back pain (LBP) have similar/different preferences?
- To what extent do participants' demographics and LBP features (patients' group) predict preferences?
- What are the underlying reasons of physiotherapists and patients with non-specific LBP to adopting certain preferences?

1.3.4 Research design

The current research study employed a mixed method design (see chapter three), in order to answer the above questions. The research was conducted in two phases:

Phase One: This phase aim to answer question one and two of the current research. Two separate survey questionnaire studies (study one and two) were carried out to evaluate physiotherapists' and patients' preferences for patient involvement in decision making and information provision when managing non-specific LBP within a physiotherapy context in Saudi Arabia. These two studies attempted to examine the overall trends in the participants' preferences as well as factors predicting or associated with these preferences. A further statistical analysis was undertaken to examine similarities and/or differences between the two groups of participants in relation to their preferences (study three).

Phase Two: this phase (study four and five) aim to address the second research question by providing in-depth knowledge about participants' views of their perceptions and views of reasons for adopting certain preferences for patient involvement in decision making and information provision and their views on facilitators/difficulties with this involvement.

1.3.5 Research aims

1.3.5.1 Aims for conducting the literature review

To review and critically evaluate the relevant literature to identify knowledge gaps in preferences for patient participation in decision making and information within physiotherapy context, when managing patients with non-specific LBP. Further objectives for this aim are detailed in the next chapter.

1.3.5.2 Aims for conducting the cross-sectional studies

These studies were carried out within physiotherapy context to manage patients with LBP, in Saudi Arabia. The aims were to:

1. identify and examine physiotherapists' and patients' preferences for patient participation in decision making.
2. identify and examine physiotherapists' and patients' preferences for information provision (giving and gathering).
3. evaluate, compare and contrast the association between preferences for patient participation in decision making and those for information provision as stated by patients and physiotherapists.
4. examine the association between patients' and physiotherapists' preferences and their perceived experiences and practice respectively during a recent physiotherapy course.

Specific objectives for each aim are detailed in chapter five, six and seven, respectively.

1.3.5.3 Aims for conducting the focus group studies

The overall aim of the focus group studies is to inform and to complement the findings of the cross-sectional studies by providing an in-depth understanding of patients' and physiotherapists' views and reasons for adopting certain preferences for patient involvement in decision making and information provision within physiotherapy context, in Saudi Arabia.

The aims were to:

- examine, in depth, patients' and physiotherapists' reasons for adopting certain preferences for decision making and information provision.
- identify patients' perceived experiences of decision making and information provision during recent physiotherapy treatment programmes.
- identify physiotherapists' perceived usual practices with respect to decision making and information giving when managing patients with non-specific LBP?
- identify and examine patients' and physiotherapists' perceived views on patient participation in making treatment decisions.
- identify and examine patients' and physiotherapists' perceived views regarding the types, modes of delivery and amount of information they wanted to gather or provide in relation to the management of patients' LBP.

1.4 Thesis structure

This thesis comprises eleven interrelated chapters, covering the study's rationale and aims, its theoretical background and the literature, methodologies and methods, empirical studies, findings, discussions, conclusions and implications for research and for practice. The contents of these chapters are outlined below.

Chapter One – introduces the thesis.

Chapter Two – discusses the following: 1) Conceptual frameworks underlying preferences for patient involvement in decision making; 2) potential theoretical constructs to understand these preferences; and 3) Literature review.

Chapter Three – discusses justifications for the research design and methodology, the methods and their sequencing, sampling techniques, data analysis and research sites.

Chapter Four – follows an account of the development and testing of two dyadic questionnaires, which involved selecting, adapting and testing two existing tools to evaluate preferences for patient involvement in decision making and information provision.

Chapter Five and Six – presents study 1 and 2: Patients' and physiotherapists' preferences for involvement in decision making and information gathering in the management of non-specific LBP

Chapter Seven – presents study 3: Similarities and differences between patients' and physiotherapists' preferences for patient involvement in the physiotherapy management of non-specific LBP.

Chapter Eight – presents the development of focus group topic guides and analysis.

Chapter Nine and Ten – presents study 4 and 5: in-depth examinations of patients' and physiotherapists' views on preferences for patient involvement in decision making and information provision, and reasons for these preferences.

Chapter Eleven – presents the overall discussion of thesis findings in relation to the theoretical perspectives and current models of SDM, clinical and research implications, study strengths and limitations, and the final conclusion.

Chapter two

Background and Literature Review

2.1 Introduction

Non-specific chronic low back pain (LBP) is a common public health problem affecting 80% of the general population at some point in their lives in developed countries (Bener et al., 2004, Longo et al., 2010); in the United Kingdom (UK), for example, 3.5 million adults are approximately affected each year (Hay et al., 2008). Although no similar nationwide data is available in Saudi Arabia, a self-report questionnaire conducted in the al-Qaseem region of the country revealed that 18.8% of 5,743 adults with musculoskeletal dysfunctions had LBP (Al-Arfaj et al., 2003). LBP is a debilitating health problem resulting in reduced function, difficulty with daily activities of such as working and sleeping, and an increase in emotional distress such as anxiety and depression (Burton, 2005, Liddle et al., 2007, Foster et al., 2008b). The cause of 90% of LBP is unclear, with little identifiable tissue damage evident and the best form of management is still unclear (Foster, 2007, Negrini et al., 2008). Although pain has been reported as the main symptom (Dionne et al., 2008, Slade et al., 2009, Kindermans et al., 2011), LBP is increasingly understood as a multi-factorial and multi-dimensional experience (Burton, 2005, Dionne et al., 2008). Hence, LBP is difficult to manage (Negrini et al., 2008).

One advocated solution is to encourage patients to participate in their care plans: they may be encouraged to express their concerns, needs and preferences when establishing management plans and deciding about treatment alternatives. Drawing upon the current literature, patient involvement in decision making is increasingly advocated as an appropriate approach to achieving a mutual clinical interaction between patients and clinicians. In addition, sharing relevant information has the potential to empower patients and encourage them to attain better facilitating good self-management (Moffett, 2002, Cooper et al., 2008). Providing patients with the information they need and involving them in making decisions has been reported to improve levels of anxiety and depression, for example in women with breast cancer

(Hack et al., 2006). While no studies in people with LBP have been found to support this, similar benefits may arise; however, examining this in the context of uncertainty surrounding the management of LBP can be challenging. Despite this, not all patients or clinicians want patients to be involved in decision making (Levinson et al., 2005, Kiesler and Auerbach, 2006, Murray et al., 2007a, Murray et al., 2007b). While a number of authors have suggested maximising the potential for patients' participation in making treatment choices and decision making by eliciting their preferences for various levels of participation in decision making (Edwards and Elwyn, 2009), the results of many studies indicate a desire by patients to adopt a more passive role: this has been shown in patients with chronic diseases such as hypertension, asthma, cardiac conditions and diabetes generally (Adams et al., 2001, Nomura et al., 2007, Burton et al., 2010)

The present chapter will review the relevant literature and examine the:

1. role of preferences in relation to current theories and models of clinical decision making.
2. clinical benefits reported to be associated with patient involvement in decision making and information provision.
3. relevant evidence of preferences for patient involvement in decision making and information provision in relation to LBP and other long term health conditions.
4. the similarities and differences between patients' and clinicians' preferences.
5. the demographic, clinical and psychosocial factors reported to be associated with preferences.
6. reasons reported by patients and clinicians for their preferences.
7. The reported match/mismatch between preferences and perceived experience/practice of clinical encounters.

2.2 Background

2.2.1 Preferences; their role in decision making and information provision

The word 'preferences' refers in general to choosing among alternatives, based on individual perceptions, interests, needs and values (Payne et al., 1992, Kahneman and Tversky, 2000, Kaplan and Frosch, 2005, Swift and Callahan, 2009). Preferences are associated with self-judgment (see below in section 2.3) and entail an individual making decisions by selecting the most desired option (Kahneman, 2003, Ortendahl, 2008).

The nature of the choice, previous experience/s, the diversity of the options and views about acceptable levels of responsibility all form the circumstances in which preferences are developed (Pitz and Sachs, 1984, Payne et al., 1992, Mellers et al., 1998, Kaplan and Frosch, 2005, Swift and Callahan, 2009). As clinicians and patients interact to select among the care options and management approaches available In clinical settings, it is important to address the preferences of all parties for decisional roles and information exchange to achieve a mutually satisfactory interaction (Thompson, 2007, Moumjid et al., 2007).

Checking these preferences at the beginning of the consultation and before any treatment option is suggested to encourage both parties to work together smoothly and minimize potential conflicts (Whitney et al., 2008). Mapping the preferences of both parties by assessing the matching level of preferences before commencing the consultation can help with identifying areas, components and circumstances where patients or clinicians have differing preferences (Flynn et al., 2006, Kiesler and Auerbach, 2006). However, involving patients in their care is a dynamic process and needs to be assessed periodically, since individuals' preferences are often inconsistent and can change with time (Payne et al., 1992, Hack et al., 2006).

Preferences for participation are often distinguished into three main types (Hack et al., 1994, Charles et al., 1997, Gafni et al., 1998, Charles et al., 1999, Gwyn and Elwyn, 1999, Doherty and Doherty, 2005, Levinson et al., 2005, Flynn et al., 2006). These are:

- **Passive role:** a preference to leave decisions to be made by clinicians.
- **Active role:** a preference to actively participate in clinical decisions.
- **Collaborative role:** patients and clinicians work collaboratively to make clinical decisions about patients' health care.

In addition, two types of preference for information provision are frequently reported in the literature: strong and weak desires (Kiesler and Auerbach, 2006). These classifications can however be misleading, as it is not clear how 'active', 'passive', 'shared', 'weak' or 'strong' these roles/desires are (Flynn et al., 2006); nevertheless, this understanding of preference roles/desires has been accepted and employed in much of the existing literature (Charles et al., 1997, Elwyn et al., 2001, Charles et al., 2004, Clarke et al., 2004, Entwistle and Watt, 2006, Makoul and Clayman, 2006, Müller-Engelmann et al., 2011).

While the evidence suggests that it may be increasingly important to encourage patients to participate in making decisions about their health care, pressurizing them to do so may paradoxically infringe their right or wish not to participate. Before assuming that participation should be the default practice, practitioners should assess patients' preferences for involvement (Deber et al., 2007). This is necessary to avoid an alternative form of paternalism (see below in section 2.2.2.1) where clinicians continue to control the decision making process through enforced patient participation. Providing patients with information is part of this process. However, giving them information they do not want or providing them with less or more than what they want can be overwhelming and contrary to their rights and to the idea of mutual agreement (Kiesler and Auerbach, 2006, van Wijk et al., 2010).

2.2.2 Conceptual frameworks underlying preferences for patient involvement in decision making and information provision

The patient's role in decision making has changed over the years and has been strongly affected by prevailing models of health care. Three distinct approaches/models are reported in the literature which describes whether and how patients could be involved in making treatment decisions about their own health care:

- ‘Paternalism’ (the clinician makes the decision),
- ‘Patient Autonomy’ (the patient makes the decision) and
- ‘Patient Involvement in Decision Making’ or ‘Shared Decision Making’ (SDM).

2.2.2.1 Paternalistic Model

In the paternalistic model, it is the clinician who makes all decisions about the patient’s health care (Charles et al., 1997, Elwyn et al., 1999b, Auerbach, 2001). This model of decision making dominated medical practice until recently (Charles et al., 1997, Elwyn et al., 1999b, Flynn et al., 2006, Edwards and Elwyn, 2009). Paternalism is defined as “the intentional overriding of a person’s known preferences or actions by another person, where the person who overrides justifies the action by the goal of benefiting or avoiding harm to the person whose will is overridden” (Nys et al., 2007). The concept of ‘avoiding harm’ may explain why some clinicians make decisions regardless of their patients’ preferences, relying on their knowledge and expertise (Emanuel and Emanuel, 1992, Charles et al., 1997, Auerbach, 2001, Flynn et al., 2006). This clinical relationship involves the unidirectional flow of decisions and related information from clinician to patient. Accordingly, no deliberation takes place between them about decisions that are to be made (Elwyn et al., 1999b), and this model has no place for patients’ preferences for participation in decision making, their values or priorities (Charles et al., 2003, Flynn et al., 2006).

2.2.2.2 ‘Patient Autonomy Model’

The ‘Patient Autonomy Model’ stands at the opposite end of the spectrum from paternalism (Ende et al., 1989, Emanuel and Emanuel, 1992, Makoul and Clayman, 2006, Edwards and Elwyn, 2009). Autonomy is defined as “regulation by the self, a construct closely related to choice and freedom, the opposite being heteronomy or controlled regulation” (Edwards and Elwyn, 2009). In this context, autonomy is seen as voluntary choice, equality and independence that is led by “self-governance” (Nys et al., 2007, Thompson, 2007). In clinical decision making, full patient autonomy means that patients make the final decisions about their health care, often after they have been provided with the necessary information by their clinicians or increasingly though sources such as the internet (Ende et al., 1989, Emanuel and Emanuel, 1992, Charles et

al., 1997, Charles et al., 1999, Flynn et al., 2006). It is considered by many to be the legitimate and moral right of individuals to exercise total freedom to frame treatment decisions with their desires and choices (Elwyn et al., 1999b, Nys et al., 2007, Edwards and Elwyn, 2009). However, it has been argued that full autonomy may endanger patient safety. Patients may make irrational decisions because they lack essential knowledge and experience; they may also under- or overestimate their illnesses, misuse resources or act irresponsibly regarding the consequences of their decisions (Towle and Godolphin, 1999, Whitney et al., 2008).

2.2.2.3 Models of 'Patient Involvement in Decision Making' ('Shared Decision Making' (SDM))

Both of the above approaches indicate an asymmetrical relationship between patients and clinicians when decisions are required (Edwards and Elwyn, 2009). Recognition of this has resulted in the increasingly common adoption of an approach where decisions and information are shared to varying degrees between the two parties (Makoul and Clayman, 2006) with the core aim of attaining legitimacy for the decisions taken (Elwyn et al., 1999a, Elwyn et al., 1999b).

A number of models have been proposed in the literature to conceptualize patient involvement in clinical decision making, reflecting the lack of clarity still underpinning both the concept and details of the process (Flynn et al., 2006, Moumjid et al., 2007, Thompson, 2007). In addition, many terms are used to describe it; these include 'patient engagement', 'patient involvement', 'patient participation', 'shared decision making', 'collaborative role', 'patient-centeredness' and 'informed choice'. This variability in determining the concept of patient involvement in decision making has resulted in further ambiguity in defining the preferences of both patients and clinicians for various roles when decisions need to be made. It has also led to difficulty in constructing valid and reliable measuring tools to examine the various dimensions/aspects of patient involvement (Charles et al., 1997, Makoul and Clayman, 2006).

The wide spectrum between clinician paternalism and full patient autonomy indicates that there are various degrees and levels of sharing, whose complexity is becoming

increasingly apparent; hence no single model can be said to represent the entire spectrum of this involvement and the models currently proposed often overlap (Makoul and Clayman, 2006). The most cited examples of these include the following (see Appendix 2.1 for the structures of these models):

1) The Model of Informed Choice (Braddock et al., 1997, Braddock et al., 1999)

2) The Model of Informed Shared Decision Making (ISDM) (Towle and Godolphin, 1999, Towle et al., 2006).

3) The Model of Shared Decision Making (SDM) (Charles et al., 1997, Elwyn et al., 1999b, Elwyn et al., 2000).

4) The Integrated Model of SDM (Makoul and Clayman, 2006).

The Model of Informed Choice model and Model of Informed Shared Decision Making underline information provision, especially at the discussion stage when making joint decisions, while the last three models aim to describe the process of SDM in terms of characteristics, practical steps and competencies. The Integrated Model of Decision Making distinguishes between the essential and ideal elements of SDM. The authors (Makoul and Clayman, 2006) propose that the 'essential' elements (these include the following: define/explain problem, present options, discuss pros/cons (benefits/risks/costs), patient values/preferences, discuss patient ability/self-efficacy, doctor knowledge/recommendations, check/clarify understanding, make or explicitly defer decision, and arrange follow-up) must be present in each consultation and are valid for use within a variety of different medical context, while the 'ideal' elements (unbiased information, define roles (desire for involvement), present evidence and mutual agreement) possibly improve the interaction. Recent work has examined the psychometric properties of a number of measures (n=7 subscales of various measures) for the presence of the essential element within the primary care settings, Légaré and colleagues (2012) examined. Only four of the measures were found to meet the criteria set out in this model, suggesting that not all tools measure the same things and they may not meet the necessary basic criteria for examining SDM.

Despite its wide use and acceptance, the Model of Shared Decision making (Charles et al, 1997) model has been criticised as it hypothesizes an ideal situation in which the ideas and expectations of the patient and clinician are in consensus, from which conflicts are absent and where patients and clinicians both accept the proposed plans and respond positively to each other. This ignores the many other factors (see below in section 2.3) that influence clinical outcomes and are often not controllable. This criticism is applicable to other current models of SDM.

Shared clinical decision making involves at least two parties – normally the clinician and the patient, though this can expand to include the multi-disciplinary team and /or families or carers. To date, these models only deal with patients' preferences and no indication is given of the role of clinician's preferences. Légaré and colleagues (2008) thought facilitating the implementation of SDM requires underpinning it with theoretical basis as well as dyadic perspectives that involve views of patients and clinicians together. However, the current models of SDM suppose that clinicians often control the entire process of decision making, while patients are only involved when they are asked for their preferences at the beginning of that process.

The existing models of SDM have been largely developed based on studies evaluating preferences for patient involvement within a single medical consultation, most often in primary care settings or in specialized medical clinics and for decisions about life-threatening conditions (Elwyn et al., 2000, Charles et al., 1997, Charles et al., 1999). None of these models was developed within physiotherapy settings, and it is important to note that the circumstances often differ – often involving long term chronic conditions that are rarely life threatening (Thompson et al., 1993, Hollen, 1994, Müller-Engelmann et al., 2011). The proposed models of SDM do not indicate whether differences in competencies exist when they are applied to the management of acute or chronic medical conditions. The management of LBP in physiotherapy context, normally involves a number of clinical sessions, often requiring long term adjustments of the patients' lifestyles , incorporating approaches to facilitate self-management and allow for the provision by the patient of continuous feedback on the treatment throughout the physiotherapy course (Cooper et al., 2008). In addition, the transferability of these models to other clinical settings, health systems and cultures

requires further examination (Holmes-Rovner et al., 1996, Braddock et al., 1997, Charles et al., 2006, Müller-Engelmann et al., 2011).

A number of potential barriers and difficulties have been identified in the literature to implement SDM. These include: suitability for application, time availability, nature of health conditions, clinicians' limited awareness of SDM, clinicians' and patients' interpersonal and communication skills, patients' and clinicians' personal characteristics and their abilities to specify preference roles (Braddock et al., 1997, Towle and Godolphin, 1999, Chapple et al., 2003, Gravel et al., 2006, Towle et al., 2006, Legare et al., 2008). In addition to above limitations, questions arise as to whether patient involvement should routinely take place intermittently over a series of stages, or whether the parties should define their preferences at the beginning of every medical encounter (Zwaanswijk et al., 2007, Whitney et al., 2008, Joosten et al., 2009, Müller-Engelmann et al., 2011). While physiotherapy practice may face similar barriers to implementing SDM with patients with LBP there is no direct evidence in the current literature to confirm this.

2.2.3 Potential theoretical constructs underpinning patients' and clinicians' preferences for patient involvement in decision making and information

In physiotherapy practice as in other areas of health care, there is a shift in clinical focus towards managing pain rather than relieving it, which is becoming increasingly evident in the physiotherapeutic management of LBP (Main and George, 2011, Nicholas and George, 2011, Foster and Delitto, 2011). Thus, identifying patients and clinicians preferences for managing LBP is crucial as their values, experiences and expectations should be involved prior to making appropriate care decisions. In relation preferences for patient involvement in decision making, this section, in two parts, reviews classic theories and models of clinical decision making and 'Self-regulation Model of Illness' as a theoretical framework to explain these preferences.

2.2.3.1 Classic theories and models of clinical decision making in relation to patients' and clinicians' preferences

Decision making occurs in all walks of life and has been studied widely but no general agreement is reported on how it should be defined (Kaplan and Frosch, 2005). Definitions commonly used in the psychological literature indicate that decision making is an act of judgment conducted through a cognitive process whose aim is to make a selection among alternatives, in order to achieve a goal (Becker and McClineock, 1967, Einhorn and Hogarth, 1981, Payne et al., 1992, Pitz and Sachs, 1984, Patel et al., 2002, Saaty, 2008). When the selection is based on relative benefits (utilities) and interests, this is known as a preference which is the topic of this thesis (Pitz and Sachs, 1984, Mellers et al., 1998, Zhang et al., 2004).

Decision making has been described as consisting of two parts (Albrecht, 1980, Baron, 1991, Garb, 2005, Saaty, 2008, Elwyn et al., 2011):

1. **A judgmental part**, which represents the cognitive function.
2. **An action part**, which represents the task function, to make choices or select among alternatives.

A number theoretical constructs have been described to underpin clinical decision making from which models have been derived. Three categories of classic theories are commonly cited in the literature. These are the normative, prescriptive and descriptive theories (Plous, 1993, Chapman and Sonnenberg, 2000, Patel et al., 2002, Garb, 2005, Elwyn et al., 2011). Examples of these theories include: the 'Probability', 'Expected Utility' and 'Multi-attribute' theories (normative), using decision trees or simulation models (prescriptive), 'Bounded Rationality Theory', 'Choice Behaviour Theory', 'Fuzzy Trace Theory', 'Information Integration Theory' and 'Image Theory' (descriptive).

- **Normative and prescriptive theories** emphasize the cognitive aspects of decision making. In this respect, the classic theories of decision making use the term 'decision-making' interchangeably with the term 'judgment' (Mellers et al., 1998). These theories often empower clinicians in their role as decision makers, clinicians assuming the responsibility, authority and knowledge to make unilateral decisions

(Gauthier and Swigart, 2003), while patients assume that their clinicians should make decisions on their behalf (Kaplan and Frosch, 2005). In addition, these models and theories underpin approaches that aim to maximize utility and to minimize risks in order to make valid, rational and logical decisions (Becker and McClineock, 1967).

Descriptive theories of decision making describe how individuals make decisions (Dillon, 1998, Chapman and Sonnenberg, 2000, Kaplan and Frosch, 2005). They represent the qualitative model of decision-making, with some psychological insights (Reyna, 2003). A number of factors have been associated with this type of decision making model, including; for example: the judgment process and behaviours, information sources and processing, the balance between utilities and probabilities, the available alternatives, confidence levels and the presentation of risk and uncertainty (Dillon, 1998, Larichev, 1999, Mellers et al., 1998, Reyna, 2003, Kaplan and Frosch, 2005).

These theories have a number of limitations. For instance, the complexities of shared decision making are poorly reflected in these theories. Elwyn and colleagues (2011) suggest that the deliberation process is the most difficult component to understand by means of the above classic theories of decision making, as they fail to define it precisely. These theories generally fail to explain the inconsistencies between choices and decision outcomes or their impact on future decisions, whether they are made by clinicians or patients (Kahneman, 2003, Kahneman and Tversky, 2000). In addition, they do not take account of the moral and ethical aspects of decision making, such as a patients' right to be involved in making decisions about their care (Makoul and Clayman, 2006, Flynn et al., 2006, Elwyn et al., 2011). Normative and prescriptive theories generally assume the availability of the appropriate information required to enable the decision-maker to choose among alternatives; however, what constitutes adequate information for the process of making management decisions is not delineated in these theories. These theories/models adopt hypothetical and sometimes mathematical approaches (such as decision trees) and do not consider individuals' values and preferences – the 'psychosocial' aspect of health care (Pitz and Sachs, 1984, Plous, 1993, Edwards and Fasolo, 2001, Patel et al., 2002, Saaty, 2008).

While this approach is effective for certain types of decision making such as making diagnosis, Patel and colleagues (2002) note that when we make many decisions, we tend neither to base our choices on mathematical procedures nor to analyse our decisions using quantitative approaches but base, for example, on values, needs, concerns and/or preferences. Besides, these theories do not help to understand the influence of patients' experience of back pain, including fear of pain and other associated psychological symptoms on their preferences and ability to participate in making care decisions.

In medical contexts, including physiotherapy, a rational decision is not necessarily an appropriate decision, since rationalization cannot occur in isolation from the circumstances within clinical encounters (including the interaction between patients and clinicians (Patel et al., 2002). In physiotherapy management of people with non-specific LBP, for example, maximizing utility (benefits) and minimising risks (undesired attributes of the illness) are related to the diverse aims and outcomes of the clinical management, including pain reduction (Noll et al., 2001) and reduction in disability (Sanchez et al., 2009), as well as levels of patient satisfaction (Hills and Kitchen, 2007), meeting of expectations (Foster, 2007, Cooper et al., 2008, Georgy et al., 2009) and better quality of life (Fritz et al., 2003).

Moreover, descriptive theories of decision making stand in isolation from other decision making frameworks and models, especially those associated with health care (Elwyn et al., 2011). These theories fail to specify the quality and amount of knowledge to be transferred or exchanged between patients and clinicians in clinical settings. No single theory seems to have the ability to explain preferences in relation to patient participation in care decisions. Although such theories are useful in describing how choices are generally made, they cannot explain reasons for why clinicians or patients tend to adopt certain preferences for sharing decisions and exchanging information.

2.2.3.2 Psychological constructs potentially underpinning preferences for participation in decision making

The illness experience can threaten a patients' ability to self-manage their health and find ways to cope with their health condition (Ogden, 2007). The severity and

chronicity of an illness can disturb someone's cognitive and physical ability to manage the insult independently (Makoul, 1998). Hence, theories and models arising from the psychological literature appear to contribute to understanding preferences for patient participation in decision making (Sivell et al., 2011).

Makoul and colleagues (2006) suggest that patient self-efficacy comprises the central determinant of preferences for participation in decision making. As such, a preference to adopt a certain decisional role (passive, active or shared) may be particularly related to patient self-efficacy as well as to their ability to cope with their illness. Previous to Makoul and colleagues suggestion, preferences for decisional roles have been suggested to result from the concept of **'reliance orientation'** (Makoul, 1998). This model divides patients into two types: 'clinician-reliant' and 'self-reliant' and was proposed to be distinguished by patient sense of responsibility; a lower sense of responsibility being associated with adopting the passive role. This sense of **'reliance orientation'** regards the perception of self-responsibility of self-control over illness as a key possible explanation for preferences for participation in decision making.

A further development of this approach is seen in the 'Self-regulation Model' (SRM), s a potential model to understand patient preferences for participation in making decisions about managing their LBP. **The self-regulation model of illness** (SRM) describes patients' sense of their medical conditions and how they perceive their abilities to overcome or cope with illness-related problems, including available treatment options (Leventhal et al., 2003). This model explains emotional reactions often associated with coping with stresses caused by illness (Cameron and Jago, 2008). Illness can cause a reduction in the patients' self-perceived control over their health, potentially compounded as they seek medical care. Thus, patient self-efficacy, as part of the SRM appears to be first affected, perhaps negatively, due to having LBP.

Patients with LBP tend to seek ways to avoid pain (Foster et al., 2008a, Huijnen et al., 2011). They tend to adopt coping strategies to manage the undesired symptoms and psychological manifestations of LBP using various approaches that can eventually appear as new presentations of their illness.

A considerable body of research has described how patients with LBP tend to cope with the severity and chronicity of their condition (Rosenstiel and Keefe, 1983, Turner and Clancy, 1986, Fernandez and Turk, 1989, Spinhoven and Linssen, 1991, Williams and Keefe, 1991, Folkman and Moskowitz, 2004). Two types of coping strategies are often observed in patients with LBP (Keefe and Dolan, 1986, Keefe et al., 1990, Jensen et al., 1991): 1) **passive coping**, where patients tend to rely on others; possibly physiotherapists, to reduce or control their pain; and 2) **active coping**, where patients cope by making various 'self- based functional efforts' (Jensen et al., 1991, Folkman and Moskowitz, 2004). Although it is still unclear what preferences patients and physiotherapists adopt for patient self-control over health care decisions, it is possible that clinically guided coping strategies may encourage patients to feel supported and feel responsible to take an action to self-control their illness and avoid complications.

Poor adherence to therapeutic exercises has been reported as a main problem in managing patients with LBP (Dean et al., 2005). However, the approach to enhance patient 'self-empowerment' through SRM framework can assist patients to gain self-confidence and encourage them to better adhere with physiotherapy therapeutic plans to manage their illness (LBP) as they recognize themselves as one main part of the process of decision making.. When decisions are made without mutual agreement between clinicians and patients, it may discourage patients from complying with therapeutic plans and decisional conflicts may arise.

The SRM suggests that patient perceptions of threat to their health can be influenced by the types of information that is gathered by patients (Hale et al., 2007). Information provision (gathering or receiving) can have a direct impact on patient perceptions of self-control over their illness and can influence their preferences to be involved in health care decisions. It is possible that exchanging information between patients and physiotherapists will empower the patients' to self-care, potentially increasing their adherence to evidence based interventions.

However, increasing knowledge alone has not been not found to be positively associated with improving adherence in patients with LBP; suggested reasons be that patients may fail to recall clinical information or integrate it effectively into their

thinking (Schneiders et al., 1998). Thus education of patients should aim not just to increase their knowledge to but to empower them to self-manage their condition on a day to day basis; patients may, for example, need information that goes beyond providing them with printed sheets on how to do exercises when they are away from the physiotherapy setting. They may prefer to *discuss* relevant information and available treatment options so they become confident about their performance when not in the clinical setting. They may also prefer to *exchange* their knowledge of illness (causes, treatments and complications) and make sure they are 'prepared' in a correct/appropriate way to take a role in the management process. Exchanging such information with patients based on their shared preferences may help with reducing their movement fears and direct their coping responses in line with physiotherapist's instructions. Hence, changing patients' behaviours to comply with clinical instructions may require moving away from considering patients as a passive recipient to play a more interacting role.

One final possible reason for patient poor adherence within the context of managing LBP, is that patients may feel neglected due to lack of a good clinical communications with their clinicians so they become discouraged and less motivated to adhere to treatment plans because of feeling not engaged (Cooper et al., 2008, Slade et al., 2009). Results from studies involving other health disciplines revealed an improvement in patients' satisfaction and adherence to medication when clinical communication is promoted and SDM is implemented during medical consultations (Dimatteo et al., 1994, Ong et al., 1995, Jahng et al., 2005, Loh et al., 2007). One explanation proposed by these authors is that patients felt involved in the clinical process, and thus become engaged in this process as they were able to reflect their values and concerns. It is also possible that patients may realize their capabilities to be responsible for their health care decisions and become able to make these decisions; sharing information and responsibility with their professionals and become more motivated to apply treatment plans and perhaps develop a higher sense of self-monitoring and controlling to reduce health threat. Yet, this suggestion will need further investigations to understand the underlying relationship between patient adherence and involved in making decisions in patients with LBP.

SRM, together with the hypothesis of 'reliance orientation', appears to propose that patients' adherence and satisfaction can be positively associated with their participation in decision making and information provision when their preferences are considered. However, several determinants may contribute to this framework; these are patients' perception of their illnesses (health threat), their knowledge of the amount and type of the threat, and their perceptions and awareness of self-control over the threat (e.g. feeling capable of and responsible for taking action and making decisions to respond to the threat), all of which are possibly influenced by demographic variables (internal factors) and situational circumstances (external factors) within specific clinical settings (Leventhal et al., 2003, Hale et al., 2007).

Understanding preferences for patient participation in decision making and information provision through the SRM can broaden traditional decision making models to include a greater patient-led component. However, this suggested relationship between preferences for SDM, clinical outcomes (e.g. adherence and satisfaction) and understanding of and responses to health threats will need to be examined and evidenced in further research.

2.3 Literature Review

In addition to discussing the background material above, it is important to review studies which have examined patient and practitioner preferences with respect to patient participation in decision making and information provision.

2.3.1 Patient participation in decision making in physiotherapy

Although SDM is reported by some to be the optimal model of clinical decision making, particularly in a setting of uncertainty (Légaré and Brouillette, 2009), current knowledge on its utilisation and effectiveness within the context of physiotherapy is very limited.

It is most common for physiotherapists to make decisions about examinations and treatment options by assessing the advantages and disadvantages of each therapeutic method, with the possible assistance of clinical guidelines (Smith et al., 2008b, Coates et al., 2001, Moffett et al., 1999), normally developed in line with current evidence-

based practice (Herbert, 2005). Therapeutic interventions include a number of aspects including assessment, diagnosis, goal setting, therapeutic interventions and the provision of advice. Some physiotherapists believed in the importance of patient involvement in setting treatment goals, still patients are not initially asked to express their preferences for participation in decision making and their participation remains limited (Wohlin Wottrich et al., 2004). While the current literature offers little evidence that physiotherapists engage their patients in most aspects of care (Foster, 2007, Arnetz et al., 2004), several studies have suggested that patient involvement in decision making, in physiotherapy, currently focuses on goal-setting and this remains limited to goal-setting activities, mostly within rehabilitation encounters.

Discussing treatment plans and negotiating care plans are reported as elements/ competencies of SDM (see the above sections). An increasing number of studies have addressed this topic. An early study in the USA, by Baker and colleagues (2001) audio-taped 73 initial physiotherapy examinations to investigate physiotherapists' attempts (n=22) to engage elderly patients (n=73) in goal-setting; using the 'Participation Method Assessment Instrument'. The findings from this study showed that only six therapists engaged their patients in goal-setting activities; however the used survey appeared to be limited in identifying physiotherapists' beliefs about patient involvement since 6 of 12 items concern other aspects in clinical interactions. This limitation of patient involvement may be attributed to physiotherapists' beliefs, their personal behaviours, their knowledge of practical steps to patient involvement, communication and clinical skills, and patients' characteristics (Baker et al., 2001, Leach et al., 2010, Wohlin Wottrich et al., 2004). Still, direct and published evidence that examine physiotherapists' knowledge and perceptions of patient involvement seems to be absent.

Not all studies have reported patient involvement in goal-setting practices to be beneficial with a systematic review of nineteen studies (Levack et al., 2006) indicating considerable variability. A number of barriers and facilitators were identified in this review, including the degree to which a patients previous experiences of physiotherapy treatment influenced their views when goals were set, the contribution of both physiotherapists and patients to identifying the treatment goals, how any

disagreements were resolved, and what information was exchanged before the goal-forum was conducted. Specific barriers identified were patients' level of understanding and difficulties in communication – in this case due to stroke.

The type of goal setting activity may be important. In in Sweden, a comparison between the clinical outcome of patient engagement in goal-settings activities and the traditional physiotherapy practice however demonstrated a better treatment outcome in patients who were involved in a 'goal forum' programme (Arnetz et al., 2004). Further factors were identified by Leach and Colleagues (2010), in Australia, who carried out semi-structured email interviews with a rehabilitation team. Eight therapists, of whom three were physiotherapists, were asked to give their opinions as to what was relevant to the goal-setting process. In this study, nature and severity of medical condition, patients' ability to participate; in addition to patient level of education were proposed to determine patient participation in goal-setting practices. Other reported factors included time available to implementing this clinical practice, types of goals and family roles in this clinical approach (Levack et al., 2011, Schoeb, 2009).

Findings from a recent study by Levack and colleagues (2011) suggest that some goals stated by patients can be unexpected or unpredictable. This finding possibly highlights the importance of exchanging clinical information as preferred by patients and therapists as a facilitator to effective goal-setting. Sobbie and colleagues (2011) have described a theoretical framework that may entail the process of goal-setting practice in the rehabilitation setting; this involves five stages: 1) Goal negotiation; 2) goal setting; 3) planning; 4) appraisal and feedback; and 5) action to carrying out with the "agreed plans". The roles of both patients and physiotherapists are not determined in this framework and it is unclear who takes charge to make decisions or whether preferences of both parties are identified before and/or throughout the process. In another study, Leach and colleagues (2010) noticed that decisional roles, can be distinguished as therapist controlled, therapist led and patient centred.

None of these studies involved patients with LBP; although these factors appear similar to those reported from other medical literature (see below in this chapter); further studies are needed to examine these in relation to patient with non-specific LBP.

It appears that patient involvement in physiotherapy practice is focussed on patient participation in goal-setting activities; this stands as a practice of physiotherapists who wanted patients to contribute to the physiotherapy care. While both goal setting and decision making require examining, the focus and aim of the above studies on goal setting rather than the process of decision making may be partly due to the current understanding of the physiotherapist's role as a 'problem solver', which highlights his or her abilities in problem solving, clinical reasoning, and identifying appropriate treatment options (Herbert, 2005, Jensen, 1999, Swisher and Page, 2005). This description of the physiotherapist as a problem solver rather than a decision maker (Smith et al., 2008a) may influence clinical interactions with patients, encouraging more passive role of patients by increasing patient their reliance on physiotherapists to help them to find solutions for their medical and physical problems requiring physiotherapy interventions. To date, evidence on patients' and clinicians' preferences for patient participation in decision making and information provision appear to be more predominant in medical literature than physiotherapy research. The next sections review this evidence; particularly in the following areas:

1. Similarities and differences between patients' and clinicians' regarding patient participation in decision making.
2. Patients' preferences and the reported associated factors.
3. Clinician' preferences and the reported associated factors.
4. Preferences for information provision.
5. The match/mismatch between preferences and perceived experience/practice of clinical encounters.

2.3.2 Similarities and differences between patients and clinicians regarding patient participation in decision making

The level of agreement between physiotherapists and patients with LBP has been studied to a limited degree in terms of how both parties perceive pain and disability

and determine problems associated with LBP, but no similar studies have been identified that examined the level of agreement between the parties in terms of their preferences for patient participation in making management choices or exchanging clinical information.

It has been previously proposed that similarities and differences between the parties in terms of perceptions, expectations and preferences for managing LBP are often influenced by its complexity and by experience within physiotherapy clinical settings (Cedraschi et al., 1996).. Studies by Grimmer and colleagues (1999) and Perreault and Dionne (2005; 2006) have identified differences in expectations. In their observational study, Grimmer and colleagues (1999) found that physiotherapists expect to develop and implement a long-term strategy to manage LBP, while patients want short-term solutions to relieve their pain. A little later, Perreault and Dionne (2005) conducted a cross-sectional study and found that lack of agreement between physiotherapists (n=9) and patients (n=78) regarding their perceptions of patients' LBP experience had influenced short-term clinical outcomes. A second study by Perreault and Dionne (2006) employed a dyad sample of patients and physiotherapists (n=78) in order to examine level of agreement between the two groups of subjects regarding their perceptions of the baseline features associated with LBP, such as pain and disability levels. It was found that agreement on pain level only was related to the treatment outcome. Although these studies address an important aspect of physiotherapist-patient perceptions and its impact on patient outcomes, they do not answer questions about the level of agreement on preferences for patient involvement in decision making and information.

In other medical settings, the similarities and differences between the preferences of patients and clinicians for patient participation in decision making have been explored in a limited number of studies (e.g. McKeown et al., 2002, Chapple et al., 2003, Stewart et al., 2004, Florin et al., 2006, Hack et al., 2006, , Burton et al., 2010). These studies have involved medical practitioners and nurses, and varied patient groups. In general, a mismatch has been observed between the two parties in relation to their preferences, regardless of the severity of the health condition and of respondents' demographic characteristics.

For example, an observation study of DM in cardiology settings revealed that cardiologists did not consider patients' preferred roles during their consultations (Burton et al., 2010), though they did involve patient in the decision making. In primary care setting, Jahng and colleagues (2005) investigated similarities and differences in patient-physician preferences for patient involvement in clinical decisions. Self-reported instruments and structured interviews were used to evaluate patients' perceptions of their participation. Two groups of patients were involved: patients reporting no serious health problems (n=74), and patients with type II diabetes mellitus (n=193). Results showed that patient-physician interaction regarding their preferences was mostly associated with patient satisfaction. However, it was unclear how patients' subjective perceptions were matched to findings obtained from the objective measures, and whether communication style during clinical interactions had an influence on the level of agreement between patients and physicians in regard to their preferences.

In nursing context, Florin and colleagues (2006) examined the preferences of nurses (n=35) and their patients (n=80), who had been admitted to a medical ward, for patient participation of DM were examined using the Control Preference Scale (CPS) (Degner et al., 1997). Results showed a significant mismatch ($p < .001$), between the parties in their preferences for patient participation: the nurses thought that patients preferred a higher degree of participation than the patients reported wanting. This overestimation of patients' desires to participate in making decisions may be due to low levels of communication between the two parties during clinical interactions.

Several reports from various medical settings examined preferences of clinicians' and patients in separate studies. This involved exploring factors associated with these preferences; in addition to addition to evaluating the match/mismatch between pre-management and experienced preferences of both parties. The next three subsections are devoted to review these studies.

2.3.3 Patients' preferences and reported associated factors

Patients' preferences for adopting certain roles in decision making within clinical settings are varied (Adams et al., 2001, Levinson et al., 2005, Chang et al., 2008),

though the traditional view has been that patients prefer a more passive role, leaving clinical decisions to be either made or controlled by their clinicians (Ende et al., 1989, Arora and McHorney, 2000).

Several studies have identified factors that may contribute to and affect preferences for decision making. These included: demographic characteristics (age, gender and education level) and severity of medical condition. However, consistent relationships between preference type on one hand and demographic characteristics or severity of condition on the other have not been clearly established. Evidence of the influence of each of these factors is now considered.

Patients' demographic characteristics

Lower numbers of patients desiring to participate in decision making with regard to their health care have been reported in association with male gender, increased age, low education level, low socio-economic status, lack of knowledge about medical care and increased trust in clinicians (Thompson et al., 1993, Hack et al., 1994, Bradley et al., 1996, Degner et al., 1997, Arora and McHorney, 2000, Adams et al., 2001, Chapple et al., 2003, Deber et al., 2007, Hamann et al., 2007, Cullati et al., 2011). This relationship between patients' demographics and their preferences is confirmed by a recent large survey study by Murray and colleagues (2007) in the Unites States (USA), in individuals with a wide variety of medical conditions (n=3177), whereas findings from a more recent study suggest that patients' preferences are unrelated to demographic variables (Burton et al., 2010). Reasons for the mixed findings may be related to the nature of the clinical decision (surgical versus medical and urgent versus routine), the severity of the medical condition and the tools used to examine preferences.

The impact of gender on patients' preferences is also subject to controversy. For example, most studies in outpatient clinical settings show that women tend to prefer a more active role (Nease and Brooks, 1995, Stiggelbout and Kiebert, 1997, Arora and McHorney, 2000, Hamann et al., 2007, Cullati et al., 2011). This preference is possibly related to women's tendency to negotiate decisions and to adopt more prominent information-seeking behaviour than men (Stiggelbout and Kiebert, 1997, Chang et al., 2008). However, a study within the nursing context by Florin and colleagues (2006)

found that patients preferred a low level of participation in deciding on acute care in hospital wards and that gender had no influence on their preferences. This difference may be related to the difference in medical settings and the type of clinicians, as patients who were admitted to hospital reported a general preference for a more passive role; it is more likely that patients who were admitted to hospital to receive acute care would wish to rely on their nurses to take charge in making medical decisions.

Nature and severity of the condition

A general observation can be made about patient preference for participation in decision making indicates that the preferences of patients in primary care settings vary; however, they appear to be generally lower in relation to more severe medical conditions and increased risk (Thompson et al., 1993, Hack et al., 1994, Bradley et al., 1996, Degner et al., 1997, Arora and McHorney, 2000, Adams et al., 2001, Chapple et al., 2003, Florin, 2006, Deber et al., 2007, Hamann et al., 2007, Cullati et al., 2011). This general pattern is possibly influenced by the absence of studies to examine in further detail their perceptions and reasons for adopting certain decisional roles.

Patients' preferences for a more passive role involved decisions made within various medical settings, such as cardiology, oncology, psychiatric illness, respiratory dysfunction and other serious medical conditions such as cancer (Ende et al., 1989, Nease and Brooks, 1995, Deber et al., 1996, Adams et al., 2001, Hamalainen et al., 2003, Janz et al., 2004, Maly et al., 2004, Levinson et al., 2005, Joosten et al., 2009, Burton et al., 2010).

Healthier individuals are reported to have stronger desires for participation in decision making. Patients' preferences for active or collaborative roles have been reported in relation to less severe conditions in dental, medical and surgical contexts (Chapple et al., 2003, Sekimoto et al., 2004, Deber et al., 2007, Murray et al., 2007a). preferences appear to be weaker in relation to more severe medical conditions and increased risk (Thompson et al., 1993, Hack et al., 1994, Bradley et al., 1996, Degner et al., 1997, Arora and McHorney, 2000, Adams et al., 2001, Chapple et al., 2003, Florin, 2006, Deber et al., 2007, Hamann et al., 2007, Cullati et al., 2011).

Cullati and colleagues (2011) conducted a mail survey among residents in Switzerland (n=2348) using the Autonomy Preference Index (API) and found that those who reported good health conditions preferred an active role in clinical decisions. In an earlier study, Stiggelbout and colleagues (1997) compared the preferences for participation in decision making of patients with cancer (n=55) and their companions with those of patients visiting surgical clinics for non-malignant conditions (n=53), using medical vignettes to describe different diseases, varying treatment options and side effects. It was noted that healthy subjects (the companions) preferred active and sharing roles. This is consistent with the health beliefs model, whereby individuals' ability to exercise self-control over their health differs according to the health threats that they face.

While this may suggest that an active role is generally preferred when individuals have minor health problems (Ende et al., 1989, Nease and Brooks, 1995), a wide range of chronic and life-threatening medical conditions (HIV/AIDS, breast cancer, prostate disease, fractures and infertility) used questionnaires employing standardised vignettes to determine preferred decisional roles and found that preferences for decisional roles were unrelated to the conditions, with more than three-quarters of the sample preferring a collaborative role (Deber et al., 2007). Again using medical vignettes including myocardial infarction, cancer and diabetes to assess preferences and the API, Mansell and colleagues (2000) found that the majority of patients (n= 255) wanted to take part in making major decisions and to be less involved in minor decisions about managing their illnesses. This finding suggests that more severe illnesses can be positively associated with patients' preferences for an active role, but it is important to note that the scenarios were hypothetical (vignettes stating "suppose that you have diabetes or other medical conditions), so respondents were not necessarily in the situation of suffering these illnesses. Again, actual and hypothetical preferences may differ.

Worsening health may affect preferences. In a cross-sectional study using the Asthma Autonomy Preference Index, patients with moderate to severe asthma (n=212) were examined for their preferences for asthma self-management (Adams et al., 2001).

When their conditions become worse, patients wanted their physicians to make the clinical decisions, regardless of the amount of information they were provided with.

Chronicity may also be important. For example, the majority of 2179 patients with chronic medical diseases (69%) preferred to leave decisions about their healthcare to their physicians (Arora and McHorney, 2000), whereas 80% of patients with acute medical and surgical conditions (n=20) preferred a collaborative or passive role, suggesting a level of contribution by clinicians to making treatment decisions. In spite of the small number of subjects involved in the latter study, it has been noted that surgical patients were most likely to prefer an active role.

The findings reported above provide contradictory accounts of the influence of demographic characteristics and severity of illness on patients' preferences for their involvement in decision making. However, other factors which should also be taken into consideration include situational circumstances (Thompson et al., 1993) such as clinicians' desire to support patient participation, clinicians' professional status, time available during clinical consultations, level of patient knowledge about decisions to be made and the severity and type of medical condition. In most of these studies, no clear data was provided concerning patients' prior experience of their illness or their level of knowledge about possible treatment options prior to assessing their preferences for involvement in decision making. It has been argued that longer experience of an illnesses may increase a patient's preference for more active participation in decision making (Mansell et al., 2000, Chang et al., 2008, Cullati et al., 2011). Most studies also fail to state whether the treatment options were discussed with patients or what level of discussion was employed. Thus, any attempt to understand the influences of demographic characteristics and of the severity of medical conditions on patient preferences for participation in decision making, in isolation from the above factors, is likely to be inaccurate and misleading, because it is not possible to make valid comparisons among these studies.

2.3.4 Clinicians' preferences and reported associated factors

Most studies have focused on patients' preferences for participation in decision making and little is known about clinicians' preferences (Murray et al., 2007b). In

addition, a relatively small number of studies have examined other aspects of decision making from the point of view of professionals. These are very varied and may address the skills and behaviours of practitioners (typically physicians) to patient participation in decision making rather than preferences.

Evidence from differing medical contexts is varied. In primary care settings, Murray and colleagues (2007) undertook a cross-sectional survey of physicians (n=1050) in the USA. Of the physicians involved, 73% preferred SDM, while only 14% preferred the paternalistic pattern. Physicians reported positive behaviours in encouraging patients to participate in decision making and to gather information during medical consultations. These results may be viewed with some caution as it was a self-report study and physicians who participated may over estimate their positive behaviours. McGuire and colleagues (2005) conducted another cross-sectional study in the USA, using in-depth interviews with physicians (n=53) from primary care and surgical specialties in private settings (dominated by the male gender). Physicians indicated their support of patients' ethical right to participate in making decisions about their health care, believing that participation can reduce potential complications and accordingly minimize physicians' legal responsibility. Moreover, physicians were positive about their role in educating patients and guiding them through the decision making process; however, this study did not examine the potential effect of either their demographic characteristics or patients' medical conditions, both factors that may mean that the results are not applicable beyond this study; since these factors can either facilitate or inhibit the implementation of SDM (Kiesler and Auerbach, 2006).
In contrast, Young and colleagues (2008) audiotaped 287 consultations, in the context of depression care in the USA, with the aim of examining physicians' adoption of SDM. Most showed negative behaviour towards involving patients to any great extent. The findings also indicated that patients' behaviour (e.g. asking questions) during the consultations influenced physicians' SDM behaviour. However, this study, involved the use of 'standardized' patients presented and this less likely to reflect the actual perceptions/behaviours.

In a more recent study in the USA, Hauer and colleagues (2011) used a checklist to examine the performance of medical students (n=60) with respect to SDM; involving standardized simulated patients. Results showed that SDM was observed in 40% of the encounters (n=243), mostly in relation to engaging the 'patients' in making intervention choices, while it was less observed during clinical communications. Since standardized patients were involved, it is possible that these findings do not reflect students' actual practice. Recent studies by Légaré and associates (2010, 2012) highlight the discrepancy between academic medical learning and day to day clinical practice when implementing SDM. The authors suggest that supporting clinicians to practice SDM through conducting educational and training programs on SDM may affect their behaviour when implementing SDM; fostering encouragement of patients' taking an active role in primary care settings.

All the above studies occurred in the USA. Other studies reported from other nations with potentially different health care systems and training have been reported . For instance, in the Netherlands, Zandbelt and colleagues (2006) investigated variations in behaviours inhibiting and facilitating a patient-centred approach among physicians (n=30) in outpatient medical services, including general internal medicine, rheumatology and gastroenterology. Consultations (n=323) were videotaped. Results showed that physicians differed in their communicative behaviours when observed in a live situation: some were less inhibiting to patients and more facilitating, some behaved conversely and others were both less inhibiting and less facilitating in Zandbelt's study, more facilitating behaviours were positively associated with increased severity of illness and symptoms reported by patients.

Clinicians' perspectives on barriers to patient involvement have been explored in a number of qualitative studies, e.g. by Elwyn et al (1999), Stevenson et al (2003) and Lown et al (2009). These studies involved small numbers of general practitioners in primary care settings. Barriers were reported in relation to clinical decision making and its outcome, the increased demands of educating patients and lack of clarity about putting SDM into practice. Factors influencing clinicians' preferences for encouraging patient participation in decision making and information provision reported in other

studies include clinicians' age; older physicians may show less SDM behaviour (Murray et al., 2007b) and level of experience; family physicians are more likely to demonstrate SDM behaviours than residents (Gagnon et al., 2010), patient level of education, situational circumstances within the clinical setting; including the time available and duration of the office visit and patients' preferences to participate in decision making (McGuire et al., 2005, Young et al., 2008).

Theses variations in physicians' behaviours and preferences for patient participation suggest that in real-world clinical settings, clinicians' behaviour does not follow rigidly the pattern suggested by clinical good practice of involving patients in healthcare decisions.

2.3.5 Preferences for information provision

Section **2.2.2.2** of this chapter delineated information provision as a distinct domain affecting patient involvement in decision making (Flynn et al., 2006, Ende et al., 1989, Hashimoto and Fukuhara, 2004). Ascertaining patients' preferences for information giving and receiving is justified by their ethical right whether to know or not about the nature of their medical condition, positive and adverse outcomes, treatment options, potential risks and complications, as well as their right to express their values and needs (Mazur and Hickam, 1997, Martin et al., 2001, Bradley et al., 1996, Murtagh and Thorns, 2006, Marteau et al., 2001). Hence, providing patients with 'sufficient' or the preferred level of knowledge was reported as a prerequisite step towards enabling patients to self-manage their medical conditions (Towle and Godolphin, 1999, Braddock et al., 1999).

In the paternalistic model, health-related information is often controlled by clinicians and it has been suggested that they should have no obligation to act as health educators (Whitney et al., 2008), whereas the collaborative model views patients and clinicians as experts, each with a special kind of experience; patients are experts in their illnesses and have experience of its impact on their lives and needs, while clinicians are expert in scientific knowledge and have experience of practising their profession. Exchanging and transferring this type of clinical knowledge between

patients and clinicians is the core of the 'patient involvement' model of decision making (Edwards et al., 2003, Marteau et al., 2001, O'conner, 1995).

SDM can be a suitable occasion to communicating medical evidence to patients. In SDM, both parties exchange their understanding of patient clinical problem/s and share thoughts about possible/appropriate management options. This level of understanding can be facilitated when patients and clinicians exchange knowledge associated with patient needs and clinical benefits. Yet, this process is increasingly influenced by a patient's expanding opportunities to access health information from other sources such as the internet. The complexity of various clinical settings entails variation in the types of information required, which should reflect patients' and clinicians' values, expectations and concerns. However, research evidence suggests that patients tend to gather information from their clinicians largely about their health care, the nature of illnesses, surgery types, potential adverse outcomes, treatment options and the course of recovery (Hack et al., 1994, Stiggelbout and Kiebert, 1997, Auerbach, 2001, Kennelly and Bowling, 2001, Kiesler and Auerbach, 2006, Chang et al., 2008).

Although SDM model suggests that information should be exchanged in two directions between patients and clinicians, clinicians' preferences for information giving are under-reported. Légaré and colleagues (2009) examined dyads consultations in primary care (n=300) and proposed suggests that during clinical consultations, patient-clinician interaction comes to a dynamic process where a behaviour and knowledge of each party has a potential to influence each other. It is unclear; in this study, how patients' and clinicians' awareness their needs to exchange knowledge and behaviours to share clinical information can be assessed in relation to implementing SDM.

While decision aids are designed to enable patients to become ready to deliberate about available treatment options (Winterbottom et al., 2008, Elwyn et al., 2009), these tools seem to facilitate a one-way transfer of knowledge from clinicians to patients in order to encourage patients to take part in deciding about their health care. Nevertheless, it has been suggested that decision aids should help patients to integrate their values and concerns with their preferences for the most effective treatment

options. In the light of this, Czaja and colleagues (2003) suggest that patient preferences act as a "predisposing factor" for information seeking behaviours, whereas the clinician's role as facilitator of this behaviour is a "reinforcing factor". In addition, the patient's existing knowledge is identified as an "enabling factor", shaping his or her information seeking behaviour. This understanding suggests that exploring patient preferences for information gathering is a key step in using decision-aid interventions that require a good quality of communication between the two parties in order to ensure successful information sharing (Godolphin et al., 2001, Martin et al., 2001).

Furthermore, Giguere and associates (2011, 2012) proposed using "decision boxes" as a framework to summarise information and make evidence-based decisions. Although these have the potential to communicate and share research-based information to patients; including benefits and harms of treatment options, none of the proposed protocols involved assessing information needs or preferences to exchange information before commencing the consultations. In addition, using multiple formats to transforming risk communication into numbers, graphics or narratives will require validation.

Level/amount of information preferred

Evidence suggests that patients vary in their desire for information: many want detailed information on health-related issues, whereas a considerable proportion prefer limited information or none at all (Kiesler and Auerbach, 2006). Patients may seek involvement in making treatment decisions when medical situations are not urgent and interventions are planned to manage chronic diseases (Braddock et al., 1997, Stiggelbout and Kiebert, 1997, Chang et al., 2008). in addition, it has been suggested that patients' desire for information is often higher than their desire for participation in decision making (Deber et al., 1996). Such findings are often obtained from cross-sectional survey questionnaires investigating desires for information provision (Deber et al., 1996, Kiesler and Auerbach, 2006) which do not investigate reasons for adopting certain preferences for information gathering or receiving. Providing patients with more information than what they want may stress them instead of educating them (Coulter, 2003, Kiesler and Auerbach, 2006).

However, Van der Weijden and colleagues (2010) thought that patients should be well "informed and knowledgeable" about treatment process before making what they refer to as 'preference-sensitive' decisions. Although their proposed qualitative study aimed to reveal ideas to assist incorporating patient preferences in clinical guidelines and adapting the later to match with patient preferences, this proposed work seems to lack clarity on the following: 1) how patient preferences for involvement can be related to their desires for information and vice-versa; 2) the influence of patients' self-abilities to make informed decisions; and 3) whether preference-based guidelines can be generalized to different patient and professional groups and other clinical settings.

Usage of information

Whatever the information desired or given, it is not known whether patients want to use it to participate in making care decisions (Ballard-Reisch, 1990, Beisecker and Beisecker, 1990, Chang et al., 2008); though discussing patients' symptoms increased the opportunities to express their concerns about the biomedical conditions presented (Zandbelt et al., 2006). Indirect evidence of usage has been found, indicating a relationship between the amount of information wanted by patients and their preferred decisional roles. In a study of breast cancer patients in the United Kingdom, Hack and colleagues (1994) report that patients who preferred active participation in decision making showed a stronger desire for information. Similarly, Hashimoto and Fukuhara (2004), having examined Japanese individuals with various health conditions (n=3395), report that those who were actively seeking information adopted a more active role in relation to decision making (Hashimoto and Fukuhara, 2004). A related suggestion is that lack of information affected patients' ability to make informed decisions (Kennelly and Bowling, 2001). It remains unclear, however, how preferences for certain decisional roles influence patients' desire for information and vice versa.

Factors affecting attitudes to information gathering /exchange

In relation to patients' demographic characteristics, younger, well-educated and female patients have shown stronger desires for information (Nease and Brooks, 1995, Asghari et al., 2008). Some studies show that women have stronger desires for information and tend to negotiate decisions about their health conditions more than

men (Chang et al., 2008, Nease and Brooks, 1995, Stiggelbout and Kiebert, 1997). In contrast, other studies have reported no gender differences regarding information seeking (Ende et al., 1989, Orsino et al., 2003). This controversy may be related to differences in clinical settings and severity of the medical condition, rather than gender, as the latter findings were observed in outpatients with high-risk medical conditions and in others with end-stage renal failure. In Iran, Asghari and colleagues (2003) found that severity of medical condition was correlated positively with information seeking desire in patients admitted to general internal medicine or surgery wards.

However, it has been suggested that situational circumstances may be more important in influencing patients' and clinicians' attitudes to information gathering/exchanging (Beisecker and Beisecker, 1990). More recent work supports this view (Thompson et al., 1993, Müller-Engelmann et al., 2011). The situational circumstances include the time available to discuss information needs, the nature of the medical condition, patients' emotional responses to the severity of their medical condition and whether medical settings require single or multiple clinical visits. The demographic characteristics and the situational circumstances of the clinical settings often influence each other in an ongoing dynamic process, which may lead to further changes in clinical communication between patients and clinicians (Bandura, 2001).

2.3.6 The match/mismatch between preferences and perceived experience/practice of clinical encounters

A few studies have also examined the level of match/mismatch between pre-management preferences and actual experienced of participation during a consultation (Burton et al., 2010, Hack et al., 2006, Murray et al., 2007b, Murray et al., 2007a, Florin, 2006). A mismatch between patients' preferred and experienced decisional roles was reported in studies in the nursing and cardiology settings (Florin, 2006, Burton et al., 2010). These findings are consistent with those reported by Stewart and colleagues (2004), who undertook a prospective longitudinal study in Canada to investigate gender differences in patients' preferences for their decisional roles and information needs. Patients were examined for their views after having

ischemic coronary events and being admitted to a coronary intensive care unit (CICU). Patients completed questionnaires in the CICU (n=906) and then mailed questionnaires six (n=541) and 12 months later (n=522). The study found that patients of both genders felt that their desire for specific information and certain decisional roles did not match with what they experienced during the care they received. A weakness of the study was that preferences for participation in decision making and information provision were not examined prior to or during medical interventions; instead, patients were asked to recall their initial preferences.

In study from Canada, Hack and colleagues (2006) conducted a longitudinal study over a three year follow-up period, in order to examine the match in preferred and experienced decisional roles of women with breast cancer (n=205), before and after surgery, using the CPS. Again, a mismatch was reported between desires and experience. Patients' experiences of involvement were associated with their quality of life but not with their preferred roles and no relationship was observed between women's preferences and their demographic characteristics or illness severity. The authors do not make it clear how patients perceived differences between decisional roles (active, passive or shared) in order to report them. Similarly, a previous study noted that patients who received treatment in dental clinics in the UK perceived themselves as accomplishing a passive role, while they would have preferred to share responsibility for making treatment decisions (Chapple et al., 2003). In this study, patients were not asked for their views of the preferred or experienced decisional roles and only their overall preferences for involvement in decision making were examined, using the CPS (Degner et al., 1997).

In contrast to the above studies, Murray and colleagues (2007) examined the match between the preferred and experienced roles of patients (n=3177) and of physicians (n=1050). While a majority of both physicians (87%) and patients (70%) felt that they practised their preferred decisional roles, physicians who preferred engaging patients in decision making reported a tendency to prolong clinical visits and to encourage patients to gather more information. In this study, patients were asked only for their perceptions of the adequacy of health information, while no objective or validated tools were used to examine participants' preferred or experienced decisional roles.

The above studies suggest that implementing SDM require translating its theoretical competencies to practical steps that take the real world of clinical practice into consideration.

2.4 Summary and conclusion

In conclusion, this review suggests that preferences of clinicians and patients for patient participation in decision making and information provision are varied. Studies on preferences took various approaches to examining clinicians' and patients' preferences for patient participation in decision making and information provision. These were mainly explored in primary care settings, sometimes involved standardized patients and some involved observation methods to examine clinicians' SDM behaviour rather than preferences. In addition, no studies were found to examine preference of physiotherapists and patients with LBP, and the reviewed studies were mostly conducted in medical disciplines other than physiotherapy and where the medical consultations described largely related to a single visit. This does not reflect the clinical circumstances most often found in physiotherapy encounters including those involving patients with LBP, where multiple clinical visits occur and where there is generally a lower risk than in much medical care. Since the reviewed studies were conducted in western countries whose culture and health systems are different from those of Saudi Arabia, the transferability of their findings to clinical practice in Saudi Arabia may require further investigation.

Chapter Three

Justifications of the Methodology

3.1 Introduction

A comprehensive review of the aims, methods and design of the current research was conducted following an exploration of the relevant literature and an analysis of the results of the pilot study. The aim was to adapt the methodological approach in light of any pragmatic factors that might influence data collection in Saudi Arabia. This chapter presents the methodological considerations and justifies the appropriateness of the chosen research paradigm and methods at the various stages.

3.2 Research Paradigm: Mixed Methods Approach

This section sets out an overview of the mixed methods approach employed and identifies the reasons for its use. The two arms of the research reported in this thesis are considered separately; overall, a mixed methods research design was adopted to improve the outcomes and to ensure that the research questions were answered fully and clearly.

3.2.1 Mixed methods: An overview

Mixed methods research has been defined as ‘‘research in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry’’ (Creswell, 2009). However, in a historical review, Johnson et al (2007) report that nineteen definitions of mixed methods were given by specialists in the field. The scope of these definitions was varied; philosophical conceptualizations, logical rationalism, practical guidelines, domains, principles, validity and orientation all formed common themes that were identified throughout (Johnson et al., 2007). The authors conclude that mixed methods research is the use of a combination of qualitative and quantitative methods which stand as a third research paradigm in itself.

Its use can be controversial. The debate as to its validity is mostly warranted by the philosophical and logical differences that underlie the qualitative and quantitative methods (Johnson and Onwuegbuzie, 2004, Johnson et al., 2007). The core of this debate is the assumption that the disparities between quantitative and qualitative methods emerge from opposing philosophical paradigms, as the two types require the implementation of different strategies towards understanding and analysing knowledge and truth. In other words, the epistemological and ontological paradigmatic orientation of each method has been said to influence the coherence and objectivity of using a mixed methods approach to collect, analyse and interpret data (Creswell, 2009).

In the light of this assessment, qualitative and quantitative research are usually presented as two distinct methodological types (Johnson et al., 2007, Dunning et al., 2008, Creswell, 2009). The methodological differences between quantitative and qualitative methods can affect their usage. Quantitative research employs a deductive perspective in testing and verifying research hypotheses or theories in an objective manner to eliminate bias, enhance validity and allow the replication of procedures. This approach considers knowledge as hypothetical, requiring rationalization and objective assessment (Sale et al., 2002, Creswell, 2009). Quantitative research can adopt various methods such as questionnaires and experimental designs and data can be generalized to different settings and populations (Johnson and Onwuegbuzie, 2004, Creswell, 2009). Data obtained from this method are numerical (including parametric and nonparametric). In order to analyse data obtained by quantitative methods, data normality, independence and equal variances are factors considered when deciding whether to use parametric or nonparametric tests. In contrast, qualitative research looks for broad patterns and uses an inductive approach to answer research questions. Qualitative methods adopt a “constructivist notion” to generate theories, describe certain phenomena, explore or explain views and ideas of the targeted sample and provide data to enrich and deepen understanding, based on small purposive samples (Johnson and Onwuegbuzie, 2004, Creswell, 2009). Methods of analysing qualitative data are typically varied (Corbin et al., 2008, Silverman, 2011). Numerous ways have been reported to analyse data obtained from focus groups; these include

ethnographic, narrative, thematic or content analysis, in addition to framework analysis (Corbin et al., 2008, Silverman, 2011, Cooper et al., 2008, Bowling, 2009).

Combinations of the two methods are increasingly utilized by researchers in disciplines including health care, medical sociology, nursing and the social sciences (Barbour, 1998, Ivankova et al., 2006), but a number of difficulties have been reported in mixing qualitative and quantitative methods, arising from two causes: differences in paradigmatic background and the practicality of implementing combined methods (Morgan, 1998, Happ et al., 2006, Ivankova et al., 2006, Creswell, 2009). However, mixing the two methods does not necessarily mean mixing their paradigms (Morgan, 1998, Johnson and Onwuegbuzie, 2004); what is more important for empirical research is to rationalize any combined procedure by explaining why this combination is appropriate for a certain study and how it is to be implemented. In other words, the feasibility of any proposed research approach, whether it uses a single or mixed methods, depends on its suitability to answer the research question(s) and on what type of data can be produced (Morgan, 1998, Robson, 2002, Ivankova et al., 2006, Creswell, 2009).

Mixed methods research can combine the individual strengths and practical benefits of the methods used, while overcoming the possible inadequacies of each method (Johnson and Onwuegbuzie, 2004, Creswell, 2009). Combining the two types can result in a rich, holistic, objective and complementary approach that cannot be achieved if a single research method is used (Morgan, 1998, Sandelowski, 2000, Johnson and Onwuegbuzie, 2004, Brannen, 2005, Happ et al., 2006, Dunning et al., 2008). Moreover, integrating the two types of method can inform theory and practice relating to a particular research question; hence, data analysis goes beyond the meaning of numbers or words in isolation from each other (Morgan, 1998, Bryman, 2006).

3.2.2 The rationale for using mixed methods to collect data for the current study

Adopting a mixed methods research design as described above has the potential to increase the scientific validity of the evidence and of the results generated. Several previous studies in the field have combined questionnaire surveys with more in-depth

qualitative approaches, (sometimes in conjunction with other methods), to explore patients' and clinicians' preferences within various medical contexts (Bhandari et al., 2003, Epstein et al., 2004, Florin et al., 2006, Deber et al., 2007, Turner-Bowker et al., 2009).

Data collection for the current study was undertaken in two phases. Answering the current research question required examining participants' opinions at a single point in time, so a cross-sectional approach employing a structured questionnaire was chosen as it standardised the items examined and increased the possibility of reaching a wider population. Since structured questionnaire studies generally produce quantitative data, the findings lack the ability to provide details that explain the underlying causes (Robson, 2002, Bowling, 2009). In order to produce an in-depth understanding of these findings, a qualitative component was subsequently conducted (Ivankova et al., 2006, Krueger and Casey, 2009). This aimed to complement the quantitative data and to provide an understanding of why and how participants had certain views concerning patient participation in decision making and information sharing about management choices (Morgan, 1998, Johnson and Onwuegbuzie, 2004, Ivankova et al., 2006).

3.2.3 Procedural considerations in using the mixed methods approach

Prior to designing the current study it was recognized that combining qualitative and quantitative methods should threaten neither the validity of the design nor the findings (Sandelowski, 2000, Sale et al., 2002, Tashakkori and Teddlie, 2003, Stewart et al., 2008). A number of designs are suggested in the literature for combining the two types of method (Morgan, 1998, Creswell and Zhang, 2009): concurrent designs, where data are collected by both methods at the same time, sequential designs, which adopt either explanatory or exploratory approaches, and embedded designs, which require either method to be supported by a major database. The advantages and disadvantages of each design are discussed extensively by Morgan et al. (1998) and Creswell et al. (2009).

The current research adopts the typological framework defined by Morgan et al. (1998) and took account of procedural considerations discussed comprehensively by

Ivankova and associates (2006). A complementary approach was employed, using a sequential explanatory design (Morgan, 1998, Ivankova et al., 2006, Stewart et al., 2008).

The current research was composed of two main phases: the quantitative phase was followed by a qualitative one, in a sequential explanatory design. In other words, the qualitative phase was explanatory, intended to provide an in-depth understanding of the questionnaire findings. The advantage of conducting the quantitative phase first was that a cross-sectional research methodology would be appropriate to investigate the tendency of individual preferences, since a larger population can be reached by such methods. However, reversing this sequence might have had the advantage of informing the construction of items for the questionnaire, which could then have been used to collect information about preferences (Elwyn et al., 2003, Elwyn et al., 2005, Ivankova et al., 2006). The following were considered reasons for choosing the current methodological sequence: 1) little information is known about patient involvement in physiotherapy decision making; 2) available knowledge of patient involvement in decision making comes from other medical disciplines and from countries quite different from Saudi Arabia; 3) there is a lack of relevant research experience in Saudi Arabia; 4) there are published reports of a number of valid tools designed to measure patient involvement in decision making; 5) previous Saudi researchers have been unsuccessful in getting in-depth information when interviewing patients.

Bearing these factors in mind, a number of steps were taken to enhance the validity of the questionnaires used in the current study (see chapter four). The questionnaire items were initially underpinned, conceptualized and adapted from the relevant literature. In addition, we conducted developmental telephone interviews with ten expert physiotherapists working in Saudi Arabia, to gather information about their routine physiotherapy practice in the Kingdom. For the abovementioned reasons, patients were also interviewed as part of the developmental pilot study, but these interviews revealed very limited information compared to that provided by physiotherapists.

In the present case, however, the goal of the quantitative part was to explore preferences of larger population, while the role of the qualitative part was to explain these findings. Thus, when the details of the sequential design were considered at the stage of planning the current research and before data collection commenced, it was decided that the qualitative data gathering would not commence until the preliminary results of the questionnaires were obtained (Ivankova et al., 2006). The preliminary findings of the cross-sectional study then formed the basis for constructing the topic guide for the qualitative phase and the results of the two phases were integrated at the stage of discussing the overall findings.

3.3 Quantitative Phase

As explained above, the quantitative phase of this mixed-methods sequential explanatory study was designed to explore the preferences of physiotherapists and patients with LBP for patient involvement in decision making and information provision in a physiotherapeutic context. This section explains and justifies the methodological choices made in designing and conducting this phase.

3.3.1 Design alternatives considered

The current evidence indicates that little information is available concerning patient involvement in decision making in a physiotherapeutic context. The scope of the current research does not extend to examining changes in perceptions or opinions over time; therefore, a cross-sectional paper-based self-completion questionnaire was developed to produce quantitative data about the preferences of patients and physiotherapists for patient participation and information provision when managing patients with LBP.

The advantages of this methodological approach include the following:

- It can help to achieve a broad recognition of more predominant views (Levin, 2006, Bowling, 2009, Creswell, 2009).

- Information generated by this method covers a wide population and this may help to identify the perceptions of a large number of participants in a relatively short time (Oppenheim, 1992, Robson, 2002, Bowling, 2009).

- Unlike case-control studies, cross-sectional ones provide a "snapshot" of respondents' views at a particular point in time, and this was found appropriate to the aim of the current study: to collect data about participants' current perceptions (Oppenheim, 1992, Boynton and Greenhalgh, 2004, Groves et al., 2004, Bowling, 2009).

Nonetheless, cross-sectional studies are not without disadvantages and may face challenges (Robson, 2002, Bowling, 2009, Creswell, 2009). Such research does not identify changes in participants' views over time and potential causal or sequencing relationships between findings cannot be captured by this approach (Oppenheim, 1992, Robson, 2002, Mann, 2003, Levin, 2006).

Alternative methods which were considered included the use of interviews and focus groups, but these encountered practical difficulties, as mentioned above. Observational techniques were considered, having been used in a number of studies concerning patient involvement in decision making, they were not considered suitable, for two main reasons: 1) the aim of the current study was to reach a large population in order to explore preferences and 2) observational methods are more appropriate for studying behaviour, phenomena and habits, rather than opinions and views (Robson, 2002, Bowling, 2009). In addition, they are time consuming and observers are prone to be influenced by the experimental setting (Mann, 2003, Bowling, 2009).

The current research employed two parallel questionnaires to produce quantitative data during the first phase. These questionnaires were developed, then tested for suitability to collect data, prior to the commencement of data collection (see chapter four). Self-completion questionnaires are typically administered impersonally and have a uniform presentation; participants give standardized responses and feel free to be direct and honest about their views while answering (Bowling, 2009, Creswell, 2009). This helps to minimize the information bias inherent in various types of interview

(Robson, 2002). Still, there are a number of potential shortcomings of using paper-based cross-sectional questionnaires, including the following:

- When used alone, they fail to provide adequately deep explanations of the phenomena being studied.
- Various types of bias can occur when conducting cross-sectional studies using paper-based self-completion questionnaire (Mann, 2003), including errors relating to questionnaire construction and the selected sampling techniques. Common questionnaire errors may involve the inadequacy or ambiguity of items, assuming positive answers and overlapping categories.

The steps that were taken to reduce the potential bias arising from the use of paper-based cross-sectional questionnaires are discussed in the following subsection.

Cross-sectional methods other than the paper-based self-completion questionnaire which were also considered for use in the quantitative phase of the current research included postal (McColl et al., 2001), face-to-face and telephone questionnaires (Oppenheim, 1992, Robson, 2002, Bowling, 2009), but these were all rejected as unsuitable because they were considered likely to yield reduced response rates and because of other potential difficulties having technical or cultural causes:

- The postal system in Saudi Arabia is an unreliable way for people to communicate and its use is very time consuming.
- Both face-to-face and telephone questionnaire administration were also considered, but it would not have been appropriate for a female researcher to use these methods to collect data from male patients, for cultural reasons.

3.3.2 Feasibility of the study design

A pilot study was undertaken in order to examine the research environment, the feasibility of the study design and potential difficulties in collecting data. Both the observations of the researcher and the pilot study findings confirmed the initial expectations regarding potential benefits of the current methodological sequence (see chapter four).

3.3.3 Potential bias

Cross-sectional research designs incorporating questionnaire surveys are subject to potential bias and error that may threaten confidence in the validity of the design and accordingly the conclusions drawn (Oppenheim, 1992, Robson, 2002, Bowling, 2009, Creswell, 2009). Sampling, measurement and non-response errors are the most common challenges associated with questionnaire surveys (Oppenheim, 1992). This section acknowledges potential bias related to the design of this phase in the present study.

3.3.3.1 Bias

Bias was possible at the early stage of developing the questionnaire and structuring the items (Oppenheim, 1992). Therefore, a comprehensive set of tests was carried out to validate the construction of the questionnaire (see chapter four). Questionnaire items were tested for face and content validity, including acceptability, wording, clarity, relevance and scoring mode. In addition, the pilot study involved testing information sheets for clarity and efficiency. In order to minimize the level of bias when completing the questionnaire, participants were also informed that there were no right or wrong answers; to reduce recall bias (Bowling, 2009), they were asked to report only the most recent experience they had had of managing LBP in a physiotherapy setting, in regard to decisions made and information shared. This part of the questionnaire was distributed towards the end of the physiotherapy programme, rather than after the treatment sessions had finished.

3.3.3.2 Sampling errors

The risk of sampling errors is discussed in detail in the next section.

3.3.3.3 Non-response bias

Steps taken to reduce non-response bias (Oppenheim, 1992, Bowling, 2009) included testing of the wording and clarity of questionnaire items and producing the questionnaires in a clear and organized layout with coloured pages. In addition, the researcher made frequent and regular visits to the research sites in order to encourage participation and enhance the distribution and return of questionnaires.

3.3.4 Sampling strategies

The number of participants approached was maximized by employing a total sample technique and accessing potential participants through the reception staff. In a further attempt to widen participation, the researcher made regular visits to the participating hospitals, during which she made contact with managers, clinical supervisors, physiotherapists and reception staff. In addition to encouraging the participation of as many participants as possible, the potential for sampling or coverage bias was addressed by considering a sampling strategy which would ensure the distribution of questionnaires to a wide range of the Saudi population (Oppenheim, 1992, Bowling, 2009). Strengthening the conclusions derived from questionnaire surveys and maximizing variety among participants (Robson, 2002, Bowling, 2009) requires a study sample which covers the research population as broadly as possible. In the present case, this meant involving as large a number of health facilities and as wide a sample of the Saudi population as possible. Steps taken to achieve this and thus to minimize potential bias related to sampling are explained in the following subsections.

3.3.4.1 Selected regions

As explained in chapter one, the population of Saudi Arabia is largely concentrated in the Makkah (West) and Riyadh (Centre) regions, but for the present study, three regions (West, Centre and East) were selected in order to cover the whole of Saudi Arabia. Within these, the cities of Jeddah, Riyadh and Dammam were chosen as representative of their respective regions and because the larger physiotherapy departments were located within them. Indeed, the majority of such departments were found to be located in Riyadh city and often to receive patients from all over the Kingdom, including the South and North regions; thus they appeared likely to represent a majority of Saudi patients with LBP. In addition, physiotherapists were also believed to be represented adequately in this sample, as the Saudi Physical Therapy Association and the main Saudi university teaching physiotherapy were located in Riyadh city.

3.3.4.2 Study sites

The government database of hospitals in Saudi Arabia (Ministry of Health, 2007) was reviewed and public hospitals in Riyadh, Jeddah and Dammam, with a capacity of five hundred beds (maximum bed capacity, which reflects workload) were initially selected. These included all types of military, university, and Ministry of Health hospitals (see chapter one). Hospitals providing tertiary care but not delivering out-patient physiotherapy services were excluded. Departments with heavy workloads were included. Large departments often have better reception services, which would facilitate the researcher's communication with the departments involved, the distribution of questionnaires and the recruitment of patients, as required by the Ethics Committee of King's College London. This was assumed because the number of working physiotherapists in an outpatient department usually reflects the workload of the service provided. It was considered inappropriate to conduct the research within small departments in public hospitals because of potential difficulties in communication with managers and supervisors, which in turn might threaten the application of ethical considerations.

The researcher was interested in including private hospitals because of potential differences in services between these and public ones. The scope of the current study was limited to the preferences of patients and physiotherapists in outpatient departments; therefore, inpatient wards were excluded.

3.3.4.3 Sampling technique

Twenty six hospitals were identified across the selected cities and invited to take part in the study. Two of these refused, so the eventual number of participating hospitals was twenty four. As the College Ethics Committee required, the hospitals were split into two groups, where patients with LBP and physiotherapists were recruited separately. This was necessary to avoid potential bias in the opinions expressed by the two groups of participants if they were recruited from the same health facilities. A simple randomization technique was employed to allocate sites to the two groups. Because of the lack of accurate information about the number of physiotherapists working within the regions concerned and on the assumption that there would be

fewer of these than of LBP patients, only eleven hospitals were randomly selected for the recruitment of patients and thirteen for that of physiotherapists.

3.3.4.4 Sample size

The decision about the appropriate sample size was discussed with a statistician (Senior Applications Analyst Advisor). Given the lack of national statistics on the number of patients with LBP in Saudi Arabia and of physiotherapists working on musculoskeletal dysfunctions, it was considered inappropriate to perform a precise calculation of the sample size before collecting data.

Approaches implemented to make the decision on sample size for this part of the research were: 1) using the number of questionnaire items to inform the sample size; 2) reviewing the relevant literature on sampling and using it as a reference; and 3) obtaining the average number of new patients with LBP seen each month in physiotherapy departments in Saudi Arabia.

1) **Using the number of questionnaire items**

It has been suggested that sample size should be calculated by multiplying the number of variables by ten (Nunnally, 1978). As there were from 34 to 36 items per questionnaire, this would give a sample size of 340-360 participants.

2) **Using relevant literature as a reference**

Published studies have included between 90 and 200 patients (Adams et al., 2001, Nomura et al., 2007) and a smaller number of clinicians (McKeown et al., 2002, Stiggelbout et al., 2004).

3) **Obtaining the average number of new patients with LBP**

In order to determine the average number of patients presenting with LBP per month, emails were sent to a number of the hospitals where patients were to be recruited to ask how many were seen there on average. Only one hospital responded and stated that the average was 27 per month. Because this was the main Ministry of Health hospital in Riyadh, with the same load of patients as the other hospitals and the same

inclusion criteria, this figure was used to estimate the size of the study population as approximately 216 patients per month for the eleven hospitals. Assuming a response rate of 50%, we anticipated 108 responses per month. This suggested that around 324 patients should be recruited as participants for the current study, but did not indicate the required number of physiotherapists.

Based on the above calculations, it was initially anticipated that a minimum of three months would be needed to recruit 324 patients, but no information was yielded about the time required to recruit physiotherapists. In the event, recruitment for the quantitative phase required over six months, during which 296 patients with LBP and 93 physiotherapists were recruited.

3.4 Qualitative Phase

The qualitative phase was designed to complement the findings of the cross-sectional study (Sim and Snell, 1996, Morgan, 1998, Ivankova et al., 2006, Hills and Kitchen, 2007, Creswell and Zhang, 2009, Creswell, 2009) as part of the mixed-methods sequential explanatory approach discussed in section 3.2.2. The following subsections report the methodological considerations taken in designing and conducting this phase.

3.4.1 Design alternatives considered

Qualitative methods using structured, unstructured or semi-structured (Robson, 2002) interviews require attention to time needed, flexibility during the interviews and the ability to control the contents; all of these depend on the interview type selected. Focus group discussions were undertaken using semi-structured probes (Hills and Kitchen, 2007, Bowling, 2009, Silverman, 2011). Several previous studies have used focus groups to elicit individuals' accounts of their preferences for patient participation in decision-making and information provision (Elwyn et al., 1999, Dolan et al., 1999, Kennelly and Bowling, 2001, McCaffrey et al., 2007, Zwaanswijk et al., 2007).

Potential disadvantages of using focus groups are discussed further section 3.4.2. Notwithstanding, the focus group was considered the most suitable qualitative

method for the current research, as it allowed the researcher to overcome cultural barriers by interviewing male participants within a group, not individually. The following additional advantages of focus groups were identified:

- Data could be collected from several participants at the same time and this allowed ten focus groups to be conducted within two months.
- It helped to stimulate participants' thoughts, since it encouraged group interaction (Webb and Kevern, 2001, Hills and Kitchen, 2007).
- Participants were able to express their thoughts openly, allowing various insights to emerge.

A semi-structured topic guide was designed on the basis of relevant literature and the findings of the cross-sectional study (Morgan, 1998, Ivankova et al., 2006). The use of such probes allowed participants' interactions to be expanded, as it encouraged multiple layers of discussion and elicited new thoughts related to the research aims (Krueger and Casey, 2009, Silverman, 2011). It also widened the dimensions explored during the discussion and stimulated dynamic but controlled discussion; participants were able to share their views on the research topic (Sim and Snell, 1996, Bowling, 2009, Krueger and Casey, 2009).

One-to-one interviews were considered as an alternative qualitative method. Exploring individuals' beliefs and views within a private setting is one major advantage of this method, but it is time consuming and when it was used in the pilot study (see chapter four), the researcher found that patients were inhibited from communicating their views. More importantly, it would have been problematic to interview male participants because this would conflict with Saudi sociocultural norms. This major concern led to the rejection of this method at the stage of research design, as it threatened to limit the amount of data collected. Other qualitative methods such as direct observation, the Delphi method, diary methods and brainstorming (Corbin et al., 2008, Bowling, 2009) were not considered suitable to address the aims of the current study.

3.4.2 Potential bias

Like any other qualitative method, focus groups are subject to a number of potential sources of bias (Daly and Lumley, 2002), which can happen before, during or after the focus group session.

The moderator can be a source of bias, as nonverbal communication, including body language and facial expressions, may influence participants' views. In order to minimize this, the interviewer was fully trained and the assistant moderator was asked to alert the researcher when necessary, using an agreed hidden sign.

The use of leading questions can bias the views expressed by respondents. In the current research, the topic guide was based on questionnaire findings, in addition to the relevant literature, and the questions were tested for relevance, suitability, wording and flow (see chapter four). No confidential issues were raised, so participants were able to express their views without feeling any pressure (Robson, 2002, Bowling, 2009).

Answers given by participants can be biased by the nature of group interaction. In order to reduce this risk, each focus group was limited to a maximum of seven participants. If any member was seen to dominate the discussion, the researcher moderated the session in order to give every member the chance to participate (Sim and Snell, 1996). Whenever extreme views were expressed, interaction within the group encouraged balanced ideas (Krueger and Casey, 2009).

Sampling is another potential source of bias. Ways of reducing this are discussed in section 3.4.3.3.

Data analysis can also be a major source of bias. Steps taken to ensure analytical rigour are discussed in chapter eight.

3.4.3 Sampling strategies

Sampling for qualitative research should aim to maximize potential variation in order to represent the range of views within the population, not to generalize these views (Byrne, 2001). The demographic characteristics of age, gender, education level and

work position (physiotherapists) were used to ensure the extent of heterogeneity or homogeneity of focus groups (Robson, 2002, Krueger and Casey, 2009). The following subsections describe the steps taken in sampling for the focus groups.

3.4.3.1 Selected regions

As pointed out in chapter one, Riyadh, the capital city of Saudi Arabia, is the location of many large public and private health facilities. Its population is large and many patients from outside Riyadh often have access to these facilities. For these reasons and other pragmatic ones, such as the limited time available to conduct this phase of the research and the difficulty for the researcher of staying in cities other than Riyadh, it was decided to run the focus group study there exclusively.

3.4.3.2 Study sites

The hospitals identified in the cross-sectional study were divided into two main categories: public and private, the former being either military or civilian, making three types in all. In order to meet the requirements of the College Ethics Committee, this was important to avoid potential bias, so it was decided to recruit patients and physiotherapists from separate hospitals. Therefore, six hospitals were randomly selected, so that one from each of the three categories was devoted to each group of participants.

3.4.3.3 Sampling technique

Purposeful sampling was used to provide a sample that was most likely to produce answers to the current research question (Marshall, 1996, Bowling, 2009). Variables involved in developing sample features were based on the findings of the cross-sectional study. These mainly involved demographic characteristics including age, gender and education level. Focus group studies of male and female patients were conducted separately, in response to cultural considerations, while physiotherapists of both genders were interviewed together at each hospital involved, since they were used to working together and to attending professional functions as one group.

3.4.3.4 Sample size

In qualitative research, the continued recruitment of participants depends on data gathered as the study progresses (Bowling, 2009); the point where no more are needed is called data saturation (Marshall, 1996, Creswell, 2009, Silverman, 2011). In the present research, the emerging themes and the trend of data provided were checked frequently. An initial decision was made to conduct one focus group at each selected hospital, but in fact while three focus groups were thus conducted for physiotherapists, there were six patients' groups in order to separate females from males, making nine groups in all. As the female group recruited from the private hospital had only two members, it was then decided to constitute an additional female group from this hospital category. Another cycle of data saturation checking revealed that no further new information was continuing to be produced, so the eventual overall number of focus groups conducted remained at ten.

3.5 Data analysis

The quantitative and qualitative data are analysed separately; however, interpretations lead to answering research questions will be integrated. The following explain approaches to analysis data revealed in each phase of the current research.

3.5.1 Quantitative data

The SPSS software package (version 19 for Windows) was used to analyse the questionnaire data.

3.5.1.1 Missing data

As a general rule, when dealing with the full set of data, only complete cases were involved in the analysis while any cases containing missing data were eliminated and the missed data was then excluded as 'listwise' (Field, 2000). The total number of participants who completed all cases (questions) is clearly stated in all relevant tables in each section/chapter.

The two parts of the patient questionnaire are not designed to be related to each other, in terms of repeating measures of patients' preferences (see chapter four for the questionnaires' development).

- **Part one (T1)** involved the first three sections of the patient-questionnaire asked about pre-management preferences. Participants provided their views before or at the beginning of a physiotherapy course to manage their non-specific LBP.
- **Part two (T2)** involved items asking patients about their experiences of being involved in decisions made , including about information received. Participants were asked to provide their views after or towards the end of their recent physiotherapy course to manage their non-specific LBP.

Despite this difference it was considered important to examine the similarities and differences between participants who completed the two parts of the questionnaire and those completed part one for homogeneity. One-Way ANOVA (the Brown-Forsythe statistics) was conducted to examine homogeneity between the two groups. This was calculated without performing a Post Hoc analysis as data were categorical and mostly presented by less than three groups, and Welch ANOVA was then carried out a 'robust' analysis (Field, 2000).

3.5.1.2 Descriptive analysis

It was necessary for the researcher to conduct a descriptive analysis to familiarize herself with the data obtained and to enable her to make decisions on what type of further analysis would be required (Bowling, 2009). Descriptive analysis was used to describe the main features observed in the data. As data were mostly categorical (non-parametric), medians (central tendencies), frequencies, percentages and cross-tabulations were computed for such responses (Robson, 2002). In addition, means and standard deviations were calculated for levels of pain, anxiety, depression and disability. Participants' demographic characteristics are presented as percentages as they were listed in categories within the questionnaires.

3.5.1.3 Inferential analysis

A number of types of analysis those were undertaken to address research questions on within and between groups differences are illustrated below. A significance level of 0.05 was adopted, so a p-value less than 0.05 resulted in the rejection of the null hypothesis at the 5% level (level of confidence = 95%). This level of significance was chosen as the principal aim of the quantitative phase is to examine the 'trend' in participants' views and factors associated with these views (Boynton, 2004).

1. The univariate analysis

Chi-squared tests were used as a preliminary analysis prior to conducting the multivariate analysis using the 'ordinal logistic regression'.

Pearson's Chi-squared and Linear-by-Linear tests were used to identify associations between proportions of expected and observed responses and differences within the same group of participants in relation to clinical, psychological and demographic characteristics; a number of these variables were transformed into categorical data for this purpose. In addition, Fisher's exact test was used when the expected values were too small and it was no longer possible to collapse more categories.

The chi-squared tests indicate the approximate probability of the results being obtained assuming no differences between the expected and observed values. This required an approximation of the values; yet the approximation required that expected values were not too small. Chi-squared requires that no more than 20% of cells have expected values less than .05 and greater than 1. When this happened, categories were collapsed during the analysis and data were transformed and given new codes. Collapsing the categories where needed may have reduced the sensitivity of the Likert scale used, as it caused some loss of categories, but it was intended to provide a reliable and accurate computation of Chi-squared test results. The formula used for computing chi-squared was

$$\chi^2 = (O-E)^2/E$$

where O = observed values and E = expected values. Table 3.1 gives examples of data transformation after such a collapse.

Table 3.1 : Examples of data transformation after collapsing categories

Original categories	Categories after collapsing
Strongly disagree + Disagree	Disagree
Neither agree nor disagree	Neither agree nor disagree
Strongly agree + Agree	Agree

The Chi-squared tests guided the selection of variables to be included in the ordinal logistic regression: independent variables (the explanatory variables) as well dependent variables (the outcome variables) that showed significant results using the Chi-squared tests at the various sections of the questionnaires were used in order to identify the most important factors to enter the ordinal regression modelling as described in the following section.

2. The multivariate analysis

Ordinal logistic regression analysis was selected for two main reasons; these are: 1) the responses to the outcome variables were ordinal and 2) to assess the effect of potential interaction effects between the explanatory variables (independent variables).

Ordinal logistic regression enables identification of potential interaction effects between the independent variables and this in case can provide a greater control and a better understanding of the effect of these factors on an examined social phenomenon (Field, 2000). The main postulation in ordinal regression is that independent variables have consistent proportional effects across the different intercepts (thresholds) (Bender and Grouven, 1997). This effect is usually referred to as the assumption of parallel lines or assumption of proportional odds. This assumes same effects of explanatory variables on the odds regardless of the intercept (Bender and Grouven, 1997).

Although ordinal logistic regression can result in predicting associations between an outcome variable and multiple independent variables (Das and Rahman, 2011), in the present study the pseudo-R square values for all models were significant, but very low (< 0.1 in all cases) indicating that there are many unknown factors that also affect each response. Therefore the models were not suitable for prediction, though parameter estimates were reported in addition to the standard errors. For each response we began with all the factors identified by the univariate analysis, and then used the method of backward elimination to simplify the model thus removing any terms whose bivariate effect can be explained by their relationship with another factor. The terms that remain can be said to have effects on the response over and above the other factors.

3. Factor analysis

Exploratory factors analysis (EFA) tests the association between items theoretical constructs and the observed responses (Field, 2000). It explores the data for factors underlying the study questionnaires and groups items that are related to one another. In addition, EFA evaluates the co-variation patterns across the correlations among items, and verifies participants' responses to questionnaire items that taking into account the way items perceived by participants, the nature of individual items (its wording) and the impact of the underlying concept that is common between other items in the questionnaires. These represent three potential types of inconsistency (variances) as following: 1) error variance; 2) unique variance; and 3) shared or common variance (Hair, 2006, Tabachnick and Fidell, 2013).

Aims for conducting Exploratory Factor Analysis (EFA), in the current study (see chapter five) were to:

1. To examine the theoretical construction of the patient questionnaire in relation to the conceptually distinct areas identified in chapter two and chapter four of the current thesis.
2. To identify factors in the patient questionnaire and examine whether the number of items could be reduced and better focused in future studies.

- **Sample size for factor analysis**

Deciding on the sample size that is required to conducting the EFA is important in order to achieve reliable correlations between variables (Hair, 2006) and to relate to the number of items being clustered/ factored (Field, 2000, Tabachnick and Fidell, 2013). However, it has been noted form the relevant statistical texts that the sample size for conducting the EFA is controversial; with a larger sample size being favoured. Five cases per item have been suggested by most of the authors (Field, 2000, Hair, 2006, Tabachnick and Fidell, 2013). This number does not fit with the physiotherapists' sample size (n=93) as this is equivalent to only three cases per item, while a sufficient number of cases per items were available in the patients' sample. Thus a decision was made to conduct the EFA with the patients' sample only, using list-wise deletion where data were missing (Hair, 2006).

In addition, for the data to be factorable, it is required that the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (MSA) be greater than 0.6 (Tabachnick and Fidell, 2013). The computed MSA for the patients' group is .0668, while it is .0446 for physiotherapists. As such, examining the differences between patients and physiotherapists in regard to their ratings/groupings around questionnaire items was found to be inappropriate since this can weaken the reliability of the correlations and accordingly threaten the conclusion. Therefore, factor analysis to study differences between patients and physiotherapists in terms of rating/grouping of questionnaire items was not done.

3.5.2 Qualitative data

As with other qualitative methods, analysing focus group data requires an objective and rigorous examination of the detailed constructions (Sim and Snell, 1996, Webb and Kevern, 2001, Creswell, 2009, Silverman, 2011). Findings yielded by this method are subjective and difficult to replicate, and meanings must always be interpreted within the context of the research area (Silverman, 2011). Rigour was achieved in analysing the focus group data in the current research in two ways: first by validating the topic guide and secondly by following a rigorous analytical approach.

The purpose of conducting the focus group study as the second phase of the current research was to complement the findings of the questionnaire survey. In order to achieve this principal aim, framework analysis was employed to identify detailed information on reasons, factors or ideas perceived by participants which might explain the questionnaire findings (van Teijlingen, 2003, Rabiee, 2004, Krueger and Casey, 2009, Silverman, 2011). The current research adopts the framework analysis as reported by Ritchie and Spencer (1994). This type of qualitative analysis (see chapter eight) takes place in systematic and sequential steps to provide a comprehensive, transparent and rigorous management of the data (Ritchie and Spencer, 1994, Krueger and Casey, 2009, Silverman, 2011). Further details on steps to analysing the obtained qualitative data are provided in chapter eight of this thesis.

3.5.2.1 Data analysis tool

The analysis was carried out using the NVivo software (version 8) (Krueger and Casey, 2009, Silverman, 2011). This computer-based method has the advantage of being a relatively fast and reliable way to analyse qualitative data, being compatible with a number of word processors, but it requires special training to enable researchers to use it effectively and correctly. NVivo can generate themes and subthemes when quotes are placed in certain locations. It can also provide quantitative data for selected words, themes and subthemes.

Chapter Four

Development and Testing of Study Questionnaires

4.1 Introduction

In light of the review reported in chapter two, a further review was undertaken between December 2007 and April 2008 to investigate the availability of an appropriate and valid instrument to be used in collecting information about the preferences of physiotherapists and patients with LBP for patient participation in decision making and information provision. This chapter, in three sections, presents this review, identifies appropriate instruments to be used as the basis on which to develop questionnaires for the current research and describes the development and testing of these questionnaires.

4.2 Literature search for the availability of an appropriate instrument to examine preferences for patient participation in decision making and information provision

The PubMed, Ovid, ISI Web of Knowledge and Scopus databases were searched for the period from January 1982 (Dy, 2007, Makoul and Clayman, 2006) to April 2008. Papers' titles, keywords and abstracts published in English were searched using the following keywords: preferences, informed decision, information provision, information sharing/exchange, patient involvement, participatory decision making, information desires, patient participation, treatment choices, patient autonomy, decisional role and patient collaborative and patient participatory role. The review was limited to published studies.

Studies were included if they described the development and testing of instruments to examine patient involvement in making treatment decisions and information provision (giving, gathering or exchanging) and included items on preferences.

Studies were excluded if the instruments:

- **a.** evaluate patient-centeredness,
- **b.** involve the use or assessment of decision-aid interventions,

c. examine the quality of decision making,

d. evaluate interpersonal clinician-patient communication,

e. measure the decision making process

4.2.1 Results of search procedure

The search procedure revealed twenty-three instruments that had been developed to evaluate various aspects of patient involvement. These covered a wide variety of domains related to patient involvement in decision making. The 23 instruments that met the inclusion criteria fell into the following categories:

- Patient involvement in decision making (14)
- Preferences for information (2)
- Patient involvement in decision making and information provision (7).

Details of the instruments in each of these categories are presented in chronological order in tables 1-3 in Appendix 4.1 For each instrument, the tables show author(s), year of publication, country where the instrument was developed, original method of administration, clinical setting and population in which it was tested, development and selection of items and their description.

In terms of their scope, the instruments were designed to evaluate:

- preferences and desires for participation and information (Hack et al., 1994, Degner et al., 1997, Ende et al., 1989, Krantz et al., 1980a, Mazur and Hickam, 1997, Thompson et al., 1993, Bradley et al., 1996, Beisecker and Beisecker, 1990, Arraras et al., 2004, Arraras et al., 2010) (9)

- patient and clinician uncertainty in making decisions (O'Connor, 1995, Dolan, 1999) (2)

- patients' or clinicians' behaviour in collaborative or shared decision making (Shields et al., 2005, Elwyn et al., 2003, Melbourne et al., 2011) (3)

- the process of SDM (Simon et al., 2006, Kriston et al., 2010) (1)

- patient perception of communication during involvement (Lerman et al., 1990) (1)
- risk communication with DM (Edwards et al., 2003) (1)
- emotional aspects of making treatment decisions as follows: self-efficacy (Bunn and O'Connor, 1996), regret (Brehaut et al., 2003) and satisfaction with decisions (Holmes-Rovner et al., 1996, Sainfort and Booske, 2000) (4)
- facilitation of patient involvement (Martin et al., 2001, Kaplan et al., 1996) (2)

Clinical settings and populations, domains, scaling and scoring, methods of administration and psychometric properties of the instruments are all discussed below.

4.2.2 Clinical settings, populations and sample selection

The main contexts in which the identified instruments were developed and tested involved primary medical practice and outpatient medical settings treating serious medical conditions such as cancer. Details of these settings are presented in tables 1-3 in Appendix 4.1 None were found that included either patients with LBP or physiotherapists. Furthermore, a number of the instruments were tested in multiple contexts in mixed health conditions; examples are the 'Decisional Conflict Scale' (O'conner, 1995), the 'Shared Decision Making –Questionnaire' (Simon et al., 2006), the 'Autonomy Preferences Index' (Ende et al., 1989) and the 'Decision Regret Scale' (Brehaut et al., 2003).

Sampling methods used in testing the instruments were varied and some had potential biases. First, the samples were generally heterogeneous in terms of medical illnesses; for example, they included both chronic and acute health conditions at various levels of severity. Such heterogeneity weakens confidence in the validity of the results, since divergent samples can result in divergent responses (Bowling, 2009, Kriston et al., 2010). Conversely, however, this heterogeneity suggests the potential for the broader use of these instruments to cover a wider range of health conditions. A second threat to the validity of the results can occur if sample populations are not

normally distributed and therefore do not represent the population in question (Streiner and Norman, 2008). For instance, more than 60% of patients from primary care settings involved in testing the SDM-Q-9 instrument were above 60 years of age.

In addition, simulated samples were used in testing a number of instruments, including the following:

- Normal subjects were trained purposefully to test the 'Rochester Participatory Decision-Making Scale' (RPDMS) (Shields et al., 2005).
- Medical students were involved in testing the Krantz Health Opinion Survey (KHOS) (Krantz et al., 1980a) and the 'Facilitation of Patient Involvement Scale' FPIS (Martin et al., 2001).

- Normal members of healthcare organizations were involved as patients in testing other instruments: the 'The Desire for Involvement Questionnaire' DIQ (Thompson et al., 1993) and the DAS (Sainfort and Booske, 2000).
- Physicians acted as patients in developing and testing the OPTION and Dyadic OPTION scales.

Using simulated samples has the potential to affect the validity of the instrument being tested, as they are unlikely to reflect the real responses, beliefs and values of the potential subjects / patients (Bowling, 2009). These observed inadequacies in the sampling techniques of these studies led to further problems in their validation (Cook and Beckman, 2006). The psychometric properties of the instruments are discussed further in below.

4.2.3 Development and selection of domains and items

The domains and items developed for the instruments varied according to their aims. Table 3.1 lists the domains covered by each tool and gives examples of the items employed. These domains and items were reviewed for their suitability to address the aims of the current research. The instruments designed to examine patient involvement in decision making all assessed one of the following three areas:

- the preferences and perceptions of patients and clinicians for patient involvement in decision making and information provision
- the competences required for the process of patient involvement in making treatment decisions
- the emotional outcomes associated with patient involvement in decision making in terms of satisfaction, confidence or regret after making treatment decisions.

- **Scoring mode**

The Likert scale was the main response mode used, in a five-point format from 'strongly disagree' to 'strongly agree', or from 'not important at all' to 'very important'. A binary response mode of 'agree' and 'disagree' was used in the 'Krantz Health Opinion Scale' (KHOS) (Krantz et al., 1980b). Further details of the Likert scale are provided in chapter five.

4.2.4 Methods of administration

Administration methods varied among the tools and reasons for the choice of methods were not always clearly justified in the published studies. Three reasons may be identified for variations in administration methods: inconsistency in defining patient involvement, differences in the domains being examined and the purposes for which the instruments were developed. The four principal methods used were the following:

Table 3.1: Examples of domains examined and items developed

Areas examined	Domains and tools addressing them	Examples of items
Competences for the process of patient involvement in making treatment decisions	Steps in SDM Shared decision making-questionnaire **(SDM-Q)**	• In the selection of the treatment method, my thoughts were taken into account just as much as the considerations of my doctor • I now know which treatment option is the best one for me • My doctor and I discussed the next steps of the treatment plan in detail • My doctor made clear that a decision needs to be made
	Physicians' behaviour in encouraging patients to participate in decision making 'Rochester Participatory Decision-Making Scale' **(RPDMS)**	• Explain the clinical issue or nature of the decision • Examine barriers to follow-through with treatment plan • Physician gives patient opportunity to ask questions and check patients
	Physicians' behaviour towards SDM (OPTION)	• The clinician identifies problem(s) needing a decision making process • The clinician explores the patient's expectations (or ideas) about how the problem(s) is/are to be managed • An opportunity for deferring a decision is provided
Emotional outcome associated with patient involvement in decision making	Satisfaction with decisions made **'The Satisfaction with Decision Scale'** **(SWD)**	• I am satisfied that I am adequately informed about the issues important to my decision • The decision I made was the best decision possible for me personally • I am satisfied that this was my decision to make
	Regret at decisions made 'Decision regret Scale' **(DRS)**	• It was the right decision • I regret the choice that was made • The choice did me a lot of harm
Preferences and perceptions of patients and clinicians for patient involvement in decision making and information provision	Decision making 'Control preference Scale) and) the autonomy Preference Index' **(CPS; API)**	• I prefer that my doctor and I share responsibility for deciding which treatment is best for me **(CPS)** • The important medical decisions should be made by your doctor, not by you **(API)**
	Information provision **'**Role and Information Preferences' **(RIP) and API**	• Even if the news is bad, you should be well informed **(API)** • Information about certain drugs prescribed **(RIP)** • Information about areas to be covered in history taking and what the patient's responses indicate regarding diagnosis and treatment (**RIP)**

Card sorting was used in two instruments: the CPS and the 'Preference For Information' (Degner et al., 1997, Hack et al., 1994). These scales were designed to be administered in the form of cards, each indicating either the most preferred decisional role or information. This method has the advantage of quick and simple administration, but it can also be confusing if the contents of the cards are not precisely explained to participants.

Written interviews were used only in the 'Patient Preference Tool' (PPT) (Mazur and Hickam, 1997). This requires answering structured questions in writing. Although this may assist in obtaining detailed information, it is time consuming and may overwhelm the participants, as they are required to put their opinions into writing.

The self-reporting paper questionnaire was the method most frequently used to collect information on the opinions and preferences of subjects. Examples are the Dyadic OPTION, API and KHOS tools. This exploratory approach is not time consuming, but it is typically subject to potential measurement biases which may affect its validity (Bowling, 2009, Oppenheim, 1992, Streiner and Norman, 2008). Such biases can be related to the sampling coverage, respondents' mood (being under pressure or having low motivation), non-response, changes to the structure of measures over time, respondents' consciousness of being studied, recall and the response mode (Bowling, 2009, Streiner and Norman, 2008). The studies identified lacked an explicit description of how such biases were either avoided or minimized. Further comments about this administrative method are provided in chapter four.

Observation by audio/video taping was employed in the case of the OPTION scale (Elwyn et al., 2003). In order to rate clinicians' SDM behaviour, two independent raters are required; this may be difficult to implement in clinical settings due to time constraints and the feeling of participants that they are being observed, which may limit the use of this scale for research purposes. The general concerns about using observation techniques, mentioned above, apply to the use of this scale. For instance, observer bias, respondents' awareness of being observed, scoring biases and floor or ceiling effects are all potential shortcomings (Bowling, 2009, Streiner and Norman, 2008).

4.2.5 Psychometric properties

Psychometric properties refer to quantifying or analysing psychological variables. Psychometrics deals specifically with designing and administering quantitative tests (Robson, 2002). To be scientifically acceptable, the quality of any assessment measure should demonstrate three basic psychometric attributes: validity, reliability and sensitivity to change (Oppenheim, 1992, Cook and Beckman, 2006). Studying these three properties can provide insights into the weaknesses and strengths of a measure, but their rigorous testing was lacking in the case of the majority of the instruments reviewed (Simon et al., 2007). Surprisingly, none of them was examined for sensitivity or specificity; their ability to identify minor changes over time is not indicated in any of the studies reviewed here.

However, certain types of reliability and validity were tested in some cases. In this review, validity and reliability testing outcomes are reported as being evident in the original studies, in addition to two published reviews conducted by Dy (2007) and by Simon and his associates (2007). Appendix 4.2 presents, in tables, assessments of the validity and reliability of the studies as reported by the authors.

Validity assessment

The testing of validity is required to ensure that an instrument measures what it is intended to measure (Robson, 2002). Not all of the identified instruments were tested for all types of validity, definitions of which are given in chapter five. In general, poor validity was found with the SWD scale and the PPT. Face validity was reported for only five instruments: the SDM-Q-9, the 'Combined Outcome Measure for Risk Communication and Treatment Decision-Making Effectiveness' (COMRADE), Facilitation of Patient Involvement Scale (FPIS), the 'Decision Emotional Control scale' and 'Decision Self Efficacy Scale', but there is no available information on other types of validity for the last two of these. Furthermore, despite being widely used in research and being translated into languages other than English, one of the main limitations of the OPTION scale is that it tends to be shifted towards observing clinicians' patient involvement behaviour depending on the dialogue that occurs

during a single consultation, which is usually controlled by the clinicians themselves, a factor which possibly affects its face validity.

Testing criterion validity was a challenge in evaluating all of the instruments examined, since no 'gold standard' tool is available in the existing literature to test items for this property. Construct validity was the most extensively studied type, using various levels of correlation with the closest similar domain(s) of the subscales.

There was noticeable inconsistency in the descriptions of the basis and sources on which the instruments were developed and a lack of clarity for the majority of the instruments (Streiner and Norman, 2008). The main approaches underpinning their development were qualitative techniques, conceptual frameworks of patient involvement, theoretical background, relevant literature, various models of informed and shared decisions and the use of existing instruments. However, it is unclear which contents of the reviewed literature, models and theories were involved; nor were the exact extraction procedures clearly explained. Among the instruments reviewed, only the authors reporting the development of the OPTION scale explicitly describe a rigorous development process in a series of studies (Elwyn et al., 1999a, Elwyn et al., 1999b, Elwyn et al., 2000, Elwyn et al., 2001a, Elwyn et al., 2005a, Elwyn et al., 2001b, Elwyn et al., 2003, Elwyn et al., 2005b).

Several studies report the use of professional and expert insight as part of the development process, yet the role and contribution of the experts are not precisely defined (PICS, API and EORTC). In addition, despite preferences and behaviours having psychological aspects and implications, only two instruments included psychology literature as part of the development process (FPIS and the Decision Evaluation Scale). The ambiguity in describing the basis on which the instruments were developed limits their construct validity and leads to further difficulties in establishing other types of validity (Fink et al., 2003).

Correlations with other existing instruments ranged from weak to moderate; possible reasons are inconsistency in defining the holistic concept of patient involvement or SDM, the diversity and dissimilarity in the scope of the instruments currently being used and the absence of a gold standard tool. Furthermore, the score formats used as

response modes in these instruments are not justified. For instance, no reasons are given for using Likert-type scales as responses to the items.

A number of instruments either tested hypothetical scenarios representing medical consultations, where patients were asked to imagine their potential involvement, or examined views by asking patients to recall their preferences after the consultations were completed. There were other factors reducing the validity of a number of the studies: hypothetical thoughts and situations do not necessarily reflect actual practice and may put individuals under psychological pressure, as they lack information about potential advantages and disadvantages associated with the choices provided which might favour the making of certain decisions (Elwyn et al., 2001a). Where studies required subjects to recall medical encounters after they had finished, this may not have yielded accurate conclusions and may also have led to confusion between preferences, wishes and regrets. Both of these approaches thus make it possible that dimensions other than preferences were actually being measured.

Although all of the measures had been either tested or piloted for validation, their content validity was confirmed only in the case of a few studies. Explanations were not always provided for word choice, the defining of items or the clarification of items that were substituted or modified before or after the testing of the instruments (Streiner and Norman, 2008). Their adaptation for use with speakers of different languages also requires further investigation and testing. For example, several of the instruments were translated from English to other European languages, but the transferability of the original meanings was not explained (Streiner and Norman, 2008, Robson, 2002). In addition, it is not known how these adaptations were influenced by differences in health systems, clinical settings, the severity of medical conditions, the quality of communication during consultations or diversity in the populations and cultures concerned.

In a structured review, Dy suggests that most of the published instruments can be adapted for use in other medical contexts (Dy, 2007); however, since most of them were developed and published between 1980 and 2000, any adaption procedure should perhaps include their revision and checking for changes within the various

health systems and medical care regimes, increasing public awareness, diversity of information sources and recent shifts in clinician-patient communication. Cultural differences may also have an impact. The majority of the instruments reviewed were developed in the United States, Canada, Germany, the United Kingdom and the Netherlands (in descending order of frequency), while none was either developed or adapted to be used in Arab countries, including Saudi Arabia.

Reliability assessment

The reliability of an instrument, reflected in its structure, can be assessed by examining its internal consistency (Cook and Beckman, 2006). A strong majority of the studies reviewed here reported values of Cronbach's α above 0.7, indicating acceptable internal consistency for the instruments concerned (Bunn and O'Connor, 1996); however, modifications or adaptation of the structures will require further testing (Streiner and Norman, 2008). The test-retest reliability was less frequently evaluated, perhaps because the stability of these instruments over time has not been studied sufficiently. Individuals' preferences are subject to change over time, partly in response to changes in the circumstances that shape their making of choices (Payne et al., 1992, Ortendahl, 2008).

4.3 Development of questionnaires on physiotherapists' and patients' preferences

It was noted, in the above section, that methodological approaches to the examination of such clinical interactions are varied. The existing instruments were found to diverge and these variations are possibly due to the lack of agreement on how patient involvement in decision making can be defined and what it should entail. However, the tools were reviewed for their suitability to be used in collecting data in the current study. It was noted that items concerning preferences for patient involvement in decision making were mostly found in two instruments: the **A**utonomy **P**reference **I**ndex (**API**) (Ende et al., 1989) and the **C**ontrol **P**reference **S**cale (**CPS**) (Degner et al., 1997). Therefore, these instruments were identified as appropriate to be used as the basis on which to develop questionnaires for the current research.

The steps taken to develop and validate the study questionnaires were underpinned by i) the relevant theoretical constructs, ii) the literature in the field and iii) the local (Saudi) clinical conditions (Streiner and Norman, 2008). The construction of physiotherapists' and patients' questionnaires went through several stages. Dyadic versions were designed with the aim of exploring the level of congruence between patients and physiotherapists. The aim of the questionnaires was to question both patients and physiotherapists to elicit the following:

- General preferences for patient participation in decision making when managing patients' LBP
- Situation-based preferences for patient participation in making specific clinical decisions involving various aspects of physiotherapeutic management of LBP
- Preferences for receiving information related to LBP
- Recent experience with patient involvement in decision making
- Patients' satisfaction with their involvement in clinical decision making and physiotherapy care (patient version).

4.3.1 Validity of study questionnaires

The content of any research instrument must be tested for validity (Robson, 2002, Bowling, 2009, Streiner and Norman, 2008, Burns et al., 2008), in order to establish that it measures what it is supposed to measure (Boynton, 2004, Boynton and Greenhalgh, 2004, Bowling, 2009). In relation to questionnaires, various types of validity require examination (Bowling, 2009, Streiner and Norman, 2008). These are: face, content, criterion and construct validity (Bowling, 2009, Robson, 2002). Definitions of these types, in addition to a description of how they were addressed in relation to the items and domains of the current study questionnaire, are provided below. Constructing procedures went through a number of stages, described below in this section. Questionnaire items were designed to present independent statements concerning preferences for patient participation in decision making and information provision. Potential response formats and types were also grounded in conceptual

and theoretical considerations derived from the relevant literature (see chapter two) (Flynn et al., 2006, Makoul and Clayman, 2006).

- **Construct validity**

Construct validity concerns the underlying concept of what is intended to be measured (Bowling, 2009). To ensure that the questionnaires had construct validity, they were underpinned by several definitions/typologies of SDM found in the relevant literature (Charles et al., 1997, Gafni et al., 1998, Flynn et al., 2006, Makoul, 1998, Smith et al., 2006); for more information see chapter two . The questionnaires were underpinned by robust theoretical constructs and checked against both these and the literature on preferences for patient involvement in decision making in other health fields, to ensure that they represented all aspects of the concept.

- **Face and content validity**

Face validity refers to whether the general appearance of the questionnaire is relevant to the area of investigation (Bowling, 2009). This is the weakest form of validity but important to ensure good respondent participation; it aims to eliminate confusion and motivate respondents to complete the questionnaires (Streiner and Norman, 2008). To achieve this, items were arranged in logical sequence for respondents to follow: sections addressing general decision making were followed by those investigating the provision of information and finally the examination of the most recent experience. They were checked repeatedly over time for relevance, sequence and wording suitability, to refine phrasing, to exclude any ambiguity and to minimize questionnaire bias (Burns et al., 2008, Boynton and Greenhalgh, 2004).

Content validity refers to the theoretical judgment about the level to which the content of a questionnaire appears to define 'logically and comprehensively' the relevant domains and to provide a theoretical structuring of the content (Bowling, 2009). Two main components were considered to ensure this type of validity (Linn, 1980), involving the following:

- Defining the questionnaire domains that were underpinned by relevant literature and theoretical constructs.

- Creating a theoretical framework to systematically assess item selection and representation of the domains.

These are explained below in sections explaining the development of the questionnaire, its structuring, the selection of items and modifications made.

Following the development process, comprehensive reviews were carried out by the research team to screen items for simplicity, sequence, consistency and clarity. The questionnaires were initially reviewed by the researchers undertaking pre-testing with three independent reviewers and finally through review by patients and physiotherapists in Saudi Arabia; this is described later in this chapter.

- **Criterion validity**

Criterion validity, also referred to as 'instrumental validity', demonstrates correlation to a valid or 'gold standard' measure (Bowling, 2009). It can be either predictive of future changes or concurrent; that is, it can corroborate or discriminate the measure in relation to concrete criteria that are evaluated simultaneously (Cook and Beckman, 2006).

At this stage of the study, statistical examination of criterion and construct validity was not carried out, since there is no agreed gold standard instrument to examine preferences for patient participation and information provision against which the questionnaires could have been compared; the selected instrument would need to be validated within Saudi culture as well as in the physiotherapy context.

4.3.2 Use of theoretical background to underpin questionnaire development

The conceptual basis and theoretical models which underpin the examination of patient involvement in decision making and preferences for this involvement are presented in chapter two and three.

The theoretical models of patient involvement and current competencies of SDM identified decision making and information provision as key distinct measurable dimensions (Ende et al., 1989, Flynn et al., 2006). The structure of the questionnaires

was therefore based on these two main domains. In addition, it is well established that types of preference for patient involvement in decision making are classified into three types or roles—active, passive and shared or collaborative—, whereas preferences for information provision are frequently indicated as either strong or weak desires. These involved three decision making styles: clinician paternalism, collaborative and full or partial patient autonomy. Responses to questionnaire items were intended to identify both preference types and information desires, so that patients and physiotherapists would be able to indicate their preferences.

Further to reviewing instruments already employed to examine patient involvement (chapter three), the literature on LBP and its management was also reviewed (chapter one). This provided a sound basis for the development of the questionnaires, including information about the functional and psychosocial impacts of LBP (Bener et al., 2006, Chanda et al., Foster et al., 2010), physiotherapists' beliefs and attitudes when managing LBP (Bishop et al., 2008, Bishop et al., 2007, Daykin and Richardson, 2004) and patients' expectations, perceptions and beliefs about LBP and its management (Cooper et al., 2008, Cooper et al., 2009). Therefore, the decision making domain of the questionnaires included statements of preferences for patient involvement in general, as well as in specific clinical situations. Items of decision making included treatment options and frequency, amount of supervision and self-management. The information domain included general statements on information needs, type of information and the extent to which patients and physiotherapists would like to exchange clinical information during physiotherapy sessions. The patient version of the questionnaire also asked for baseline information about LBP, including levels of pain, disability, anxiety and depression.

4.3.3 Use of the literature on preferences to underpin questionnaire development

The literature examining patient preferences in decision making is described in chapter three. In relation to patient involvement, reviewing current instruments revealed the absence of an instrument to examine clinicians' preferences; in addition, no instrument was found to be independently adequate to examine all aspects of

patient involvement in treatment decisions. Thus, while the use of relevant literature to inform the construction of new tools, scales or questionnaires (Streiner and Norman, 2008) is an approach that has been used extensively in previously published works examining patient involvement in decision making (see chapter three), the use of any of the existing instruments would have lacked precision, as its validity to be used in the context of physiotherapy and patients with LBP would have been questioned (Streiner and Norman, 2008, Bowling, 2009, Bunn and O'Connor, 1996).

Notwithstanding these inadequacies, two instruments were identified as suitable to form the basis of the development of the study questionnaires. Both related to patient preferences, however, as none was identified that related to those of clinical practitioners. The **Autonomy Preference Index (API)** (Ende et al., 1989) and **Control Preference Scale (CPS)** (Degner et al., 1997) were chosen because they were designed to examine preferences for decision making and information provision. A description of these tools is provided below in this section. Once **API** and **CPS** had been selected, both tools were reviewed thoroughly, then adapted to be used as the basis of the construction of questionnaires for the current study (Streiner and Norman, 2008, Bowling, 2009).

In order to address the aims of the questionnaire described above, it was necessary to integrate material from the two tools and to add some condition-specific material, as described below.

The **Autonomy Preference Index** was originally developed to examine patient preferences for autonomy in decision making and information acquisition. The instrument was tested among 312 patients in primary care settings in the United States. It is divided into two domains: 1) fifteen items on preferences for decision making, comprising six general items and nine related to one of three medical vignettes (hypertension, myocardial infarction and upper respiratory tract illnesses); 2) eight items on information seeking. A final section of this instrument explores patients' satisfaction with their involvement in decision making and information acquisition.

The vignettes employed suggest various levels of severity of conditions; the API requires patients to 'suppose' and imagine their situation when they are exposed to a certain level of severity. The medical vignettes involve hypothetical scenarios which may not be applicable to patients with LBP, thus compromising the validity of the instrument, and which may influence the logical process of making choices (Weber and Johnson, 2009). The API has been widely employed in studies examining patients' preferences for decision making and information acquisition in relation to various medical conditions, including hypertension, cardiac problems, asthma, schizophrenia, multiple sclerosis and breast cancer (Hamann et al., 2007, Nomura et al., 2007, Adams et al., 2001, Gibson et al., 1995). Information about the validity and reliability of the API is provided in chapter three.

The API is scored using a five-point Likert scale format, ranging from 'strongly disagree' to 'strongly agree'. Item scores are transformed into a 0-100 scale format of degree of preference, where 0 indicate no preference, 50 indicates a neutral choice and 100 indicates the strongest preference for involvement.

The **Control Preference Scale** was developed to measure the amount of control that patients want in relation to their involvement in making decisions (Degner et al., 1997), defined as "the degree of control an individual wants to assume when decisions are being made about medical treatment" (see Appendix 4.3 for the original scale). Information provision is not part of this scale; rather, it is concerned only with an overall or global preference for involvement in decision making. The CPS was originally developed within breast cancer populations. It can be administered in the form either of 'cartoon' cards or of general statements and involves face-to-face administration. Each card shows the role preferred by the individual, classified as follows: active role, collaborative role and passive role (Degner et al., 1997). The five cards (roles) are ordered in a hierarchy design and respondents are asked to select preference that they want, using a 'pick one' technique. The 'shared or collaborative role' was positioned in the middle of this scale, while the other choices indicate a preference for who makes the treatment decisions or takes the lead in making them.

The CPS is short and easy to administer and summarizes the overall control preferred by an individual, but it does not include items about information desires; therefore, it is usually used with other instruments to collect data about patient participation in decision making (Gore et al., 2005, O'Donnell et al., 2007). It was originally administered in face-to-face data collection, but was also used as a five-point scale that is added to other questionnaires (Janz et al., 2004, Florin et al., 2008). The latter approach has the advantage of facilitating the use of the scale and avoiding potential confusion arising from the use of cards. Degner and colleagues (1997) describe various ways to analyse the data obtained from the CPS, including the use of simple frequencies of the preferred roles selected, ordinal categorical analysis using cross-tabulation and chi-squared tests.

4.3.4 Use of practitioner expertise to underpin questionnaire development

In order to inform the development of the questionnaires, telephone interviews were conducted with clinicians in Saudi Arabia to ensure that the section addressing preferences for participation in the various elements of LBP management reflected current physiotherapy practice. It was necessary to identify locally common clinical scenarios concerning physiotherapy practice and the management of LBP, in order to inform the section addressing this element. This matching was necessary to validate the use of the questionnaires to collect data on preferences for patient involvement in the physiotherapeutic care of patients with LBP in Saudi Arabia. The researcher obtained the professional views of ten expert Saudi physiotherapists, each with more than ten years' experience of working with patients with LBP. This was important for generating and/or adapting questionnaire items to reflect common practice.

As noted in chapter four, prior experience of conducting needs assessments in Saudi Arabia has shown that patients—who are not used to being asked their opinion with respect to health care—are very reticent to provide information similar to that elicited from the therapists. Patients' insights were therefore obtained at the stage of evaluating the patient questionnaire.

Telephone interviews with physiotherapists

Ten physiotherapists were approached in the cities of Riyadh (5 therapists), Jeddah (3 therapists) and Dammam (2 therapists). They worked at different types of hospital: military (5 therapists), university (2 therapists), Ministry of Health (2 therapists) and private (1 therapist). These participants were either senior physiotherapists or clinical supervisors in their departments and had more than ten years of clinical experience of physiotherapy. They were asked in telephone interviews to provide information about normal physiotherapy procedures as well as the clinical pathway, if any, for managing LBP in their facilities.

Similarities were evident across the organizations in the physiotherapeutic protocols that physiotherapists reported for managing LBP. They indicated that patients with LBP were often referred to physiotherapy departments from specialized medical clinics within the same hospital (orthopaedic, neurological, neurosurgical and primary care in outpatient units). Reasons for these clinics to refer patients to physiotherapy departments included managing pain and symptoms related to LBP, promoting the functional activity levels of individuals with LBP and providing patient education while encouraging self-management.

Once a patient was referred, a history was taken and a physiotherapy examination performed. After this examination, physiotherapists would often decide on the appropriate treatment modalities and/or approaches. Patients were commonly provided with information concerning their LBP problem and the exercise that they should take at home. Physiotherapists would decide whether patients needed supervision during the physiotherapy sessions. The number of treatment sessions varied; it was the therapist who decided on the number of visits and who discharged patients based on the management of symptoms (pain relief/reduction and improved physical abilities). Some physiotherapists preferred to incorporate a two-week follow-up period, after which patients were normally re-evaluated before a full discharge from physiotherapy services. Physiotherapists working in military hospitals reported a well-established policy of clinical pathways regarding patient management, while other hospitals did not state such policies or clinical guidelines; however, all

physiotherapists were similar in having full autonomy to make clinical decisions regarding the treatment of all of their patients. Table 4.1 summarizes the main domains of information provided by physiotherapists.

This information elicited from physiotherapists was used as the basis of the development of domains and items for the questionnaires used in the current study. The information obtained assisted the adaptation of existing questionnaires, where original scale items were either adapted or removed, while other items were added. Further details on the API and CPS items used, adapted and discarded are provided below.

Table 4.1 : Main domains elicited in interviews with expert physiotherapists on routine physiotherapeutic management of patients with LBP

1.	How patients with LBP are referred to the physiotherapy department
2.	Reasons for referring to physiotherapy department
3.	Physiotherapy history taking and clinical examinations
4.	Choosing treatment options/ management approaches
5.	Number of treatment sessions, frequency of visits and appointments
6.	Amount of supervision
7.	Discharge plans
8.	Information given by physiotherapists to patients about their LBP condition and proposed physiotherapy treatment

4.3.5 Construction of patient and physiotherapist questionnaires

The patient questionnaire was developed first and then formed the basis of the physiotherapist questionnaire. The following subsections describe the steps undertaken to construct patient and physiotherapist questionnaires respectively.

4.3.5.1 Structure of patient questionnaire

The structure of the API was used as a template for the patient questionnaire, because it comprised two main domains related to the aims of the current study—decision making and information provision (Ende et al., 1989)—and because it matched the aims of the study specified above. The objective was to integrate the questionnaire domains with the study aims and to create a framework that would

ensure content validity. The newly developed questionnaire had the following sections:

a. Preferences for patient participation in decision making, exploring three types of decision making: 1) general preferences for decision making; 2) situational preferences concerning who should make the decision in certain clinical circumstances; 3) overall preferences for making treatment decisions.

b. Preferences for information provision or gathering.

c. Recent personal experience with the physiotherapy programme, exploring the most recent experiences of patients or physiotherapists regarding perceived patient participation in decision making and information provision.

d. Patient satisfaction with decisions made and information gathered during physiotherapy sessions (patient version only).

Questions on demographic characteristics and LBP baseline features (patient version) were also added to the questionnaires. These factors were found to influence individuals' preferences for patient involvement (chapter three). The demographic section, placed at the beginning of the patient questionnaire, contained questions about age, gender, region of residence, education level and housing type. In order to provide baseline information about patients' conditions and their physiotherapy management (Cooper et al., 2008, Bener et al., 2006), items were added to the patient questionnaire to elicit self-reported perceptions of intensity and location of LBP, levels of disability, anxiety and depression (Dionne et al., 2008, Foster et al., 2008, Foster et al., 1999, Foster et al., 2010, Bener et al., 2006), onset of physiotherapy programme and number of treatment courses (see Appendix 4.4).

Information yielded by these questionnaires were anticipated to draw an image about the overall condition of LBP (Pallant and Bailey, 2005, Sanchez et al., 2009, Dionne et al., 2008, Foster et al., 2008, Chanda et al.). These questionnaires were translated and validated to be used in Saudi Arabia and other Arabian countries (Elrufaie and Absood, 1987, Bener et al., 2004). These included the following:

1. Hospital Anxiety and Depression Scale (HADS)

HADS is a self-reporting scale (see Appendix 4.4) that is frequently used to identify and quantify levels of anxiety and depression(Annunziata et al., 2011) . It was first developed in 1983 and composed of 14 items with a Likert scale formatting in a 4-point scale (from 0 to 3) indicating the symptoms within the last seven days. The scale was translated and adapted to number of languages including Arabic (Elrufaie and Absood, 1987). Although HADS was designed to identify emotional distress that is not caused by certain somatic illnesses (Annunziata et al., 2011), the use of this scale is becoming more common when examining anxiety and depression related to chronic conditions; including LBP (Pallant and Bailey, 2005). It has been previously suggested by Apkarian and colleagues (2004) that abilities of patients with chronic to decision-making tasks are impaired. The current study, aimed at examining influences of anxiety and depression associated with LBP on patient preferences for participation in decision making and information provision.

2. Modified Ronald Morris Disability Questionnaire

The Roland–Morris disability questionnaire was first developed in 1983 as a self-administered scale that aim to measure disability level (daily activities) in individuals with LBP (Roland and Morris, 1983). It looks at functional abilities of patients with LBP, and therefore it was decided to use it in the current study. The questionnaire was considered as one of the most common and valid outcome measures for LBP (Roland and Fairbank, 2000). It was used in research work in several versions: its original version of 24 items where (0) indicates 'no disability' and (24) indicate 'higher disability'. Other modified versions were also used; within variants number of items: 23, 18, 16, 12 and 7. Reasons for the variations in these are related to time specification or replacing the yes and no responses with a Likert scale.

Another modified version with 21 items was adapted from the original scale to be used to collect data about patients with LBP in the United Arab Emirates (see Appendix 4.4). The validity of the later version is questioned since the validation process was not enough clarified and the Arabic version has one item repeated

(Bener et al., 2006). A recent study by Sanchez and colleagues (2009) provided an evidence of patient preferences for areas of disabilities that have been indicated by patients with LBP as treatment priorities; however, the current study aimed at examining the influence of disability on patient preference to take part in decision making or gather clinical information.

3. Numerical pain scale

Chapter three highlighted pain as a major influencing factor affects the whole experience of patient with LBP as well as patient preferences for involvement in clinical decision making. The numerical pain scale of 11-points from 0 (no pain) to (10) maximum pain (Dionne et al., 2008, Hjermstad et al., 2011) was used, to determine back pain intensity as reported by participants who took part in the current study (see Appendix 4.4). The literature evidenced the numeric pain scale of 11-points as simple reliable, self-reporting and subjective tool to quantify pain intensity/severity across patients with chronic pain (Labus et al., 2003, Gramling and Elliott, 1992).

4. Body Chart

A body chart (see Appendix 4.4) was also used as part of the survey to indicate pain location as reported by participants. This was used in the current study as an indication of severity of LBP condition (Dionne et al., 2008).

The physiotherapists' version contained questions about level of clinical experience, workload of patients with LBP, types of LBP commonly seen and types of hospital where physiotherapists worked. These were all added in order to examine their influence on physiotherapists' preferences for patient involvement in decision making and information provision (Daykin and Richardson, 2004, Bishop et al., 2008, Bishop et al., 2007).

- **Items selected from the API and CPS**

As noted above, the API contains general statements about preferences for treatment decisions that were initially used in primary care settings, while the CPS was originally

used to explore the overall preferences of patients with breast cancer for the amount of control they would have over their treatment choices.

a. Autonomy Preference Index

The API vignettes were all removed; while maintaining the overall structure, items related to who should make the decisions were replaced with new phrases indicating physiotherapy practice in managing LBP in Saudi Arabia. Items excluded included those which were not suitable to be adapted to indicate physiotherapy clinical scenarios, which did not address the current research questions or which explored levels of anxiety and functional abilities. The items removed are listed in Appendix 4.5.

Items selected from the API for use in the current study were those concerned with participation in decision making, information provision and patient satisfaction with the medical care they received from their doctors.

b. Control Preference Scale

All of the five statements included in the CPS were selected, adapted then added to the current study questionnaires as one distinct item (item 18 in the final version), indicating the overall preference for patient participation in decision making.

- **Item wording**

Both the CPS and the API were developed outside the context of physiotherapy; thus, statements contained the word 'doctor' and phrases such as 'my doctor', which were changed to 'physiotherapist' and 'my physiotherapist' in the patient questionnaire. The passive voice or use of the pronoun 'you' or the word 'patients' in 'the patient should' in the API was changed to 'I should' as patients expressed their preferences. The items selected from the CPS and the API, before and after adaptation, are presented in Tables 4.2 and 4.3. For example, "The important management decisions should be made by the doctor, not me" was adapted to "The important management decisions should be made by the physiotherapist, not me'.

Table 4.2 : Items selected from the CPS before and after adaptation

Decisional Role	Original Items	Items after adaptation (Patient Version)
Active Role	**a.** I prefer to make the decision about which treatment I will receive **b.** I prefer to make the final decision about my treatment after seriously considering my doctor's opinion	I prefer to make the decision about which treatment I will receive I prefer to make the final decision about my treatment after seriously considering my physiotherapist's opinion
Collaborative Role	**c.** I prefer that my doctor and I share responsibility for deciding which treatment is best for me	I prefer that my physiotherapist and I share the responsibility for deciding which treatment is best for me
Passive Role	**d.** I prefer that my doctor makes the final decision about which treatment will be used, but after seriously considering my opinion **e.** I prefer to leave all decisions regarding treatment to my doctor	I prefer that my physiotherapist makes the final decision about which treatment will be used, but after seriously considering my opinion I prefer to leave all decisions regarding treatment to my physiotherapist.

Table 4.3 : Items selected from API before and after adaptation

Original Items	Items after adaptation
Current study aim: To explore general perceptions of preferences for decision making	
The important medical decisions should be made by your doctor, not by you.	The important management decisions should be made by the physiotherapist, not me
Patients should go along with your doctor's advice even if you disagree with it.	I should go along with the physiotherapist's advice even if I disagree with it
Hospitalised patients should not be making decisions about their own medical care	Patients in physiotherapy departments should not make decisions about their own physiotherapy care
Patients should feel free to make decisions about everyday medical problems.	I should feel free to make decisions about my physiotherapy management
Patients should decide how frequently you need a check-up.	I should decide how frequently I should be seen by my physiotherapist
Whether you should be seen by the doctor	I should decide whether I need a follow-up physiotherapy appointment
Whether you should take some time off from work to relax	Whether I should change/adjust my routine daily activities
When you will be ready to go home	Whether I should do a home management programme following my visit to the physiotherapy department.
When you will be ready to go back to your usual activities	When I am ready to carry out my routine daily activities
Whether your heart specialist (cardiologist) should be consulted	When a more senior physiotherapist should be consulted about my LBP management.
Current study aim: To explore preferences for information provision	
As patients become sicker you should be told more and more about your illness	If the level of my back pain changes, I should be given more information about what is happening to my back
Patients should understand completely what is happening inside your body as a result of your illness.	I should have a good understanding of my LBP
Even if the news is the bad, you should be well informed.	If the news about my back pain is bad, I should be fully informed
Doctors should explain the purpose of your laboratory test tests.	Physiotherapists should explain the purpose of any physiotherapy clinical examinations that they use when assessing my LBP
Patients should be given information only when you ask for it.	I should be given information only when I ask for it
It is important for patients to know all the side effects of your medication.	It is important for me to know all the possible adverse effects of any physiotherapy interventions used to manage my back pain
When there is more than one method to treat a problem, patients should be told about each one	When there is more than one method to treat my LBP, I should be informed about each one

Informing a patient is as important as treating him	Informing patients is an essential part of any physiotherapy management for LBP
Current study aim: To explore perceptions of recent experience with medical care/physiotherapy care	
In your most recent experience with the doctor you have just seen, how much did you participate in the decision that was made?	In your most recent experience with the physiotherapist, how much did you participate in the decision-making process?
My role in making these decisions was	How much did you participate in the decision-making process?
If you are sick, as your illness became worse, you would want the doctor to take greater control	Do you think that the severity of your pain affected how much you wanted to be involved in the decisions made?
Current study aim: To explore satisfaction with decision making	
I'm very satisfied with the medical care I receive	I am very satisfied with the physiotherapy I received
There are things about the medical care I receive that could be better	There are things about the physiotherapy I received that could have been better
I am pleased with how decisions were made	I was satisfied with how decisions were made

- **Development of new items**

New items were based on the professional insights of the expert physiotherapists, with the aim of reflecting clinical physiotherapy practice in managing LBP in Saudi Arabia. These items were structured, then added to the new tool (Appendix 4.6).

4.3.5.2 Structure of physiotherapist questionnaire

The physiotherapists' version of the new questionnaire was developed in order to form a dyadic pair with the patient questionnaire. Item wording was changed to indicate physiotherapists' preferences, as shown in Appendix 4.7.

4.3.6 Scoring of items and analysis

A five-point Likert scale (Likert, 1952, Robson, 2002, Bowling, 2009) was used as a scoring format for all items in the two questionnaires. The scale had previously shown good psychometric properties (Streiner and Norman, 2008) and had been used in most measures examining patient involvement reported in the literature (Bradley et al., 1996, Holmes-Rovner et al., 1996, Bunn and O'Connor, 1996, Martin et al., 2001, Brehaut et al., 2003); see the literature review chapter for more examples. In relation to the current study, the selection of this scale format was based on the nature of the questionnaire items (Streiner and Norman, 2008). Categories of the Likert scale used indicate negative and positive responses in a form of continuum to indicate preferences (Bowling, 2009, Robson, 2002), decisional roles (active, collaborative and passive) and information desires (strong or weak).

Key labels used in the patient questionnaire to describe preferences for decisional roles and information desires are presented in Appendix 4.8. The original summation procedure used in API to compute preferences was not used here; instead, data from the study questionnaire were subjected to ordinal categorical analysis according to the observed responses (Degner et al., 1997, Streiner and Norman, 2008). These indicated certain decisional roles (active, passive or collaborative) that were preferred by respondents, in addition to the level of desire for providing or receiving information. The preference for decisions being controlled by patients was considered an active role, whereas a preference for decisions to be controlled by physiotherapists was considered passive. Leaving decisions to be made by physiotherapists alone was labelled a full passive role (paternalistic pattern in respect of physiotherapists), whereas leaving the full decisions to be made by patients alone was designated as full patient autonomy. Where the preference was for decisions to be made with equal responsibility of both parties, this was labelled a collaborative role or SDM.

4.4 Testing study questionnaires

The previous section described the development of the study questionnaires. Testing a questionnaire for suitability to collect data relevant to the study aim is a fundamental step that should be undertaken prior to collecting data for any study (Oppenheim, 1992, Boynton and Greenhalgh, 2004); hence, this section describes the process of testing the questionnaires.

4.4.1 Aims of testing the questionnaires

Primarily, the testing process aimed at establishing the face and content validity of the questionnaires. Testing them for potential structural problems and their ability to explore preferences as intended was a prerequisite step prior to collecting data about preferences, to ensure content validity (Boynton and Greenhalgh, 2004). To ensure face validity, it was also necessary to test the relevance of the items, to assess the acceptability and suitability of each questionnaires to be used with its target population, to refine its wording, improve clarity and remove any degree of ambiguity

(Bowling, 2009, Streiner and Norman, 2008). Additional aims of the testing procedure included assessing the time required to complete the questionnaires, familiarizing the researcher with the environment in which the fieldwork was to be conducted and assessing the suitability of the study design for collecting data on subjects' preferences.

4.4.2 Stages of evaluating the questionnaires

In order to ensure face and content validity, the evaluation of the questionnaires was carried out in two stages: first, a pre-pilot study was conducted in London, then the main pilot study was performed in Riyadh.

4.4.2.1 Preliminary UK-based evaluation

- **Aim**

The aim of this stage of the evaluation was to examine the face and content validity of the questionnaires with physiotherapists treating patients with LBP, including identifying problems with questionnaire structure, the relevance of the items and their wording.

- **Participants**

Purposive sample was used (Bowling, 2009) to ensure the selection of participants who were most likely to offer objective thoughts about the questionnaire structure and items at this stage; hence, the selection was based on their level of clinical experience and academic background. Physiotherapists (n=3; one female and two males) who treated patients with LBP as part of their routine clinical practice and who had more than three years' clinical experience of treating such patients were approached by the researcher in person and via email. They were invited to participate and provided with an account of the study's aim and what participation would entail. Their age ranged from 28-30 years. The two male therapists were PhD candidates in an academic physiotherapy department, while the female was a full-time clinician working in a hospital.

Eliciting the opinions of patients in the UK was considered inappropriate at this stage, because of cultural differences between the UK and Saudi Arabia and dissimilarities in physiotherapy management of patients with LBP.

- **Procedure**

The time and date of conducting the interviews was arranged with each participant separately. On attendance, each was informed about how the session was to be conducted and was given a copy of the study questionnaires. The session was carried out on individual basis and consisted of:

a. Completing the physiotherapist questionnaire to examine its structure, the domains and the relevance, clarity and wording of the items, in addition to the time required to complete the questionnaire.

b. Reviewing the patient questionnaire to examine domains and structure, item relevance, clarity and wording.

c. Ranking questionnaire items for priority and importance in order to ensure focus and effectiveness.

d. Interviewing participants at the end of the session in order to receive feedback about the questionnaires.

The time taken to complete the questionnaire was noted and once participants had completed the physiotherapist questionnaire and reviewed the patient questionnaire, they were provided with a ranking sheet to complete (CD Appendix 1). Ranking questionnaire items entailed choosing what they considered the most important questions and reordering the chosen items according to their perceived suitability for inclusion in the questionnaires (Toner, 1987). If an item was selected only once or twice, this was taken to indicate that it was less important, not core to practice or possibly repetitive, whereas if it was selected by all participants, then it was considered very important. When certain items were not selected at all, the participants were asked to give a reason.

Further review was undertaken based on participants' feedback and comments. Following the ranking procedure, a semi-structured interview was conducted and audio-taped with the participants' written permission. Questions in the interview were mainly concerned with questionnaire structure, the relevance and clarity of items and the face validity of the two versions. Table 4.4 lists the topics covered in the interviews.

Table 4.4 : Topic guide for pilot study interviews

Category	Questions
Structure	Were sections and subsections clearly presented? Was the overall structure appropriate?
Scoring	Was the scoring format appropriate and easy to understand?
Layout	Were the layout and the font size appropriate?
Items (content and relevance)	Were the items relevant to the study aim, concise and logically ordered? Were the statements overlong or complex? Were common clinical scenarios of managing patients with LBP fully addressed?
Wording	Were the words used clear and easy to understand? Were there any difficult, ambiguous or confusing words?
Additional comments	What do you think is the value of conducting such a study? Do you have any additional comments or suggestions that would make the questionnaires better?

- **Results**

Participants commented that the research topic was important and that they considered the questionnaire domains to be relevant to the research topic. Items related to physiotherapy practice for managing patients with LBP were found to be appropriate and adequate to portray common clinical scenarios.

No participant reported ambiguity in any of the items. In general, the questionnaire items were found to be appropriate, clear and relevant to the aim of the study. However, participants suggested that a few items should be either reworded, amended or omitted, as they were considered redundant; for instance, they noticed a repetition in two of the items in section one: question 17 (When I should be discharged from physiotherapy services) and question 18 (Whether my views should be taken into account in the discharge plan). Participants therefore suggested

omitting question 18 in this case. Table 4.5 lists such items and the amendments made.

Table 4.5 : Amendments to questionnaire items

Original Items	Amended Items
If my back pain gets worse, I should be given more information about what is happening to my back.	If the level of my back pain changes, I should be given more information about what is happening to my back.
If my back pain gets better, I should be given more information about what is happening to my back.	
On any occasion when your LBP was mild, how much did you participate in the physiotherapy decisions that were made?	Omitted
On any occasion when your LBP was severe, how much did you participate in the physiotherapy decisions that were made?	
When you were seriously disabled due to your LBP (severely limited daily activities), how much did you participate in the physiotherapy decisions that were made?	

Results produced by the ranking procedure placed the items in two categories, based on their priority and importance: the less important items and the very important ones (see CD Appendix 1). The less important items were those associated with whether patients would like to have a role in treatment decisions; these items were considered by participants as unimportant.

- **Conclusion**

Overall, questionnaire domains and items were reported to be relevant, clear and suitable. A few amendments were made in response to participants' feedback and comments. These involved omitting repeated items and rewording others. However, since this pre-pilot study was undertaken in the United Kingdom, participants' views were likely to have been influenced by their cultural background, level of knowledge and nature of practice in healthcare settings different from Saudi ones. Therefore, further testing was carried out in Saudi Arabia.

4.4.2.2 Exploratory studies in Saudi Arabia

- **Design**

A cross-sectional pilot study of twenty patients with LBP and twenty physiotherapists treating musculoskeletal dysfunctions was carried out between 29th April and 30th May 2008 in Riyadh.

- **Aim**

The aim of this pilot study was to ensure face and content validity by examining the perceptions of patients and physiotherapists regarding the acceptability of the questionnaires in the proposed research environment. The objectives were:

- to examine the acceptability, relevance to the study aim and feasibility of the newly developed questionnaires within the context of physiotherapy management for patients with LBP in Saudi Arabia.
- to identify potential problems in conducting the main study, to pilot the information sheets (see CD Appendix 2) and to pilot the questions concerning demographic characteristics and baseline features of LBP (Boynton et al., 2004).

- **Participants**

a. Patients with LBP

Patients were included if they were aged 18 years and above, had non-specific LBP with or without nerve root involvement, were attending physiotherapy for treatment and were able to read Arabic. Patients with specific LBP related to serious pathological conditions, such as tumours, fractures or cauda equina syndrome, were excluded (Dionne et al., 2008).

b. Physiotherapists

Physiotherapists were included if they had clinical experience in treating patients with non-specific LBP of least 2 years, were registered at the Saudi Commission for Health Specialists (so their practice was periodically monitored and also authorized) and

managed patients with LBP as a routine part of their clinical practice (seeing at least three patients per week).

- **Procedure**

1. Sampling

The number of subjects required to evaluate the content and structure of questionnaires continues to be debated (Boynton and Greenhalgh, 2004). However, a questionnaire needs to be tested until an investigator becomes confident that no further changes are required and that saturation of data obtained has been achieved. It was decided to start with twenty participants in each group of subjects, and data was checked for saturation according to the responses and comments obtained (Robson, 2002, Bowling, 2009). Purposeful sampling was considered an appropriate technique to recruit participants for both groups (Bowling, 2009), ensuring heterogeneity in terms of their socio-demographic characteristics in order to inform the pilot study.

2. Recruitment

a. Site selection

Patients from all over the Kingdom had access to the main hospitals located in Riyadh; therefore, it was appropriate to conduct the study in this city. Different types of hospitals were included, as was intended for the main study. Four main hospitals located in Riyadh were randomly selected. These were two military, one university and one Ministry of Health hospital. The researcher approached the heads of the physiotherapy departments at these hospitals by email and telephone, gave them a full explanation of the study and asked permission to approach their staff and patients with LBP to recruit participants for the study. Agreement was obtained from department managers and local ethical approval was required and obtained for the Ministry of Health Hospital (CD Appendix 3). On arrival in Riyadh, the researcher made a preliminary visit to each department and provided further explanation of the procedure.

b. Recruitment process

Upon arrival in Riyadh, the researcher conducted a preliminary visit to managers of physiotherapy departments at the four hospitals to explain the aim of the pilot study, the process for conducting it, the recruitment criteria and the number of participants required initially for piloting the questionnaire. The managers identified physiotherapists working in outpatient services and treating patients with LBP, who were then approached by the researcher and invited to participate. The researcher then asked these physiotherapists to identify patients with LBP so that she could approach them in person, invite them to participate and provide them with information sheets.

c. Protocol to evaluate the questionnaires

The time and date for conducting the evaluation was arranged with each participant separately. On attendance, a participant was informed about how the session was to be conducted. Each session was carried out on individual basis and consisted of the following:

- Completing study questionnaires to examine the domains, the structure and the relevance, clarity and wording of items, in addition to noting the time required to complete the questionnaire.

- Ranking questionnaire items for priority and importance in order to ensure focus and effectiveness.

- Interviewing participants at the end of the session in order to obtain feedback on the questionnaires.

Once they had completed the questionnaire, participants were provided with a ranking sheet to complete (CD Appendix 4). Ranking the items entailed choosing what they considered the most important ones and reordering them according to their priority for inclusion in the questionnaire (Toner, 1987). If an item was selected fewer than five times (a maximum of 25% of responses), this was taken to indicate that participants considered it less important, whereas any that was selected by all participants was considered very important. Where certain items were not selected

at all, participants were asked to give a reason. Following the ranking procedure, semi-structured interviews were conducted and audio-taped with the participants' permission in writing. Interview questions focused on the content validity, domains and structuring of the questionnaire, the relevance and clarity of items and the face validity of the two versions; these questions were the same as those used in the preliminary interviews (Table 5.8).

Physiotherapists' interviews were audio-taped with permission then transcribed, while because of cultural considerations, patients' comments were all noted in writing and then shown to each patient after the interview, in order to confirm their comments.

d. Translation procedure

The patients' version of the questionnaire was translated into Arabic; however, based on information obtained from Saudi physiotherapists at the stage of developing the questionnaires (see previous section), it was decided to keep the physiotherapists' version in English, since physiotherapists working in Saudi Arabia usually use English for purposes related to professional practice and scientific discussion, rarely using Arabic on such occasions. The researcher translated the patient information sheet from English into formal Arabic, using the simplest and most basic wording possible. Further review of the translated texts was carried out by three independent bilingual and local reviewers in Saudi Arabia (Ballout et al., 2011), then back translation was undertaken by an independent authorized translation office in Riyadh (Harkness, 2004). A comparison between the original and back-translated versions was then undertaken by an independent reviewer, a bilingual Saudi physiotherapist. The outcome of the review process showed strong similarities between the two versions. However, a simple alternative translation for the phrase 'I should' was suggested. In addition, translation of the interview transcripts was carried out by the researcher and checked by an independent reviewer, a senior physiotherapist with more than ten years' experience of managing patients with LBP.

Data saturation was checked as interviews were progressing (Silverman, 2011). Recruitment of participants from both groups of subjects was stopped once no new information was generated during the interviews.

- **Results**

a. Results of testing patient questionnaires

1. Demographics

Twenty patients with LBP participated. Demographic characteristics, pain intensity and whether this was the first time they had received physiotherapy are presented in CD Appendix 5.

2. Responses to questionnaire items and comments

Patients were satisfied with the clarity of questions related to their demographic characteristics and clinical features of their back pain, but they suggested that questions concerning pain intensity should be more specific, to indicate time of pain onset. All twenty patients completed a questionnaire and the scores resulting from their responses to the questionnaire items are presented in CD Appendix 6. These results primarily demonstrate that the patients were able to complete the questionnaires satisfactorily. An exemplar of these responses is shown in Table 4.6 later in this section. It was noted that the responses, despite such a small sample, were not skewed towards certain categories of the Likert scale; rather, the observed spread of scores indicated that patients' responses were scattered.

The time required by patients to complete the questionnaire ranged between 20 and 35 minutes. None of the items was reported as irrelevant, with questionnaire layout and items described as suitable. Patients stated that the questionnaire was clear and not difficult to complete, with only one patient suggesting that questions needed attention. One patient also suggested adding an item encouraging physiotherapists to consider patients' opinions.

Only a few patients (5/20) ranked questionnaire items by level of importance. Questions ranked highly were: "The important management decisions should be

made by the physiotherapist, not me", "I should go along with the physiotherapist's advice even if I disagree with it", "I should normally participate with my physiotherapist about making decisions for my LBP management", "What type of treatment I should receive in the physiotherapy department" and "Whether I need to be referred back to my treating physician"; this was in addition to the item on the overall preference for patient participation in decision making and the whole section on preferences for information gathering. Other patients were not willing to select questions or decide on prioritization; they apparently considered all items to be equally important.

Table 4.6 : Example of patients' responses to questionnaire items

General Preferences for Decision Making	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
Making important decisions	0	0	1	8	11
Going along with physiotherapist's advice	0	2	2	7	9
Making decisions about physiotherapy care	2	7	2	7	3
Frequency of clinical visits	2	4	3	8	3
follow-up physiotherapy appointment	1	6	1	9	3
feeling free to make decisions	4	5	3	6	2
Normally participate in making decisions	0	2	2	8	7

b. Results of testing physiotherapist questionnaire

1. Demographics

Twenty physiotherapists participated; their demographic characteristics are presented in CD Appendix 7 which shows that half of them were novice practitioners. The most commonly seen LBP cases were found sub-acute or chronic LBP associated with nerve root involvement.

2. Responses to questionnaire items and comments

Questions about demographic characteristics were reported to be clear. The responses of the twenty physiotherapists are presented in CD Appendix 8 and an exemplar of the responses is shown in Table 4.7 in this section. As with the patients'

group, the responses were spread across the Likert scale categories, indicating a wide range of responses.

Table 4.7 : An example of physiotherapists' responses to questionnaire items

Rated as important	Physiotherapists' General perception of their preferences for decision making	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
16	Making important decisions	1	3	4	5	7
7	Going along with physiotherapist's advice	2	8	5	4	1
9	Making decisions about physiotherapy care	3	7	2	5	3
0	Frequency of clinical visits	8	10	2	0	0
3	follow-up physiotherapy appointment	2	14	3	1	0
8	feeling free to make decisions	5	5	5	4	1
16	Normally participate in making decisions	0	2	3	8	7

The preferred language for physiotherapists in conducting this questionnaire was English and the time required to complete it ranged between 10 and 25 minutes. Physiotherapists found its layout to be suitable.

Items were judged relevant, clear and in good sequence, although participants noted repetition in "When a patient should be discharged from physiotherapy services" and "Whether patient's views should be taken into account in the discharge plan". None of the physiotherapists reported any difficulty with reading, understanding or completing the questionnaire, although some noted the need to pay attention while going through it. However, one physiotherapist suggested that the item "When a more senior physiotherapist should be consulted about patient's LBP management" should be reworded to improve clarity, while another suggested adding an item concerning situations of conflict between therapist and patient over the making of treatment decisions. Most of the physiotherapists stated that this questionnaire could be used in relation to all clinical cases requiring physiotherapy management.

All questions in section 1 part A were described by some of the physiotherapists as important, except one: "Patients should decide how frequently they should be seen by their physiotherapists". Questions 1 and 7 were the most frequently selected items (each by 16 respondents). The adapted items of the Control Preference Scale were also selected. Examples of these are the following: "Patients should have a good understanding of their LBP", "Informing patients is an essential part of any physiotherapy management for LBP, "Do you think that the severity of a patient's

pain affected how much she/he wanted to be involved in the decisions made by you?", "Whether a patient should change/adjust her/his routine daily activities", "Whether a patient should do a home management programme following her/his visit to the physiotherapy department" and "Decisions about the management of a patient's LBP were made by". The majority of the questions in all sections were rated as important, although physiotherapists were asked to rate a limited number of items.

Physiotherapists suggested adding a question in section three, on the most recent experience of managing patients with LBP, to specify patients' characteristics in terms of age and education level so that their answers would become more relevant.

- **Amendments**

a. Amendments to patients' questionnaire

Amendments involved items concerning general perceptions of patent participation in decision making and items of patients' recent experience with physiotherapy care. Items were either reordered or replaced with a more straightforward structure and some new items were added. Amendments made to the patient and physiotherapist questionnaires are presented in CD Appendix 9.

- **Conclusion**

Exploring the preferences of physiotherapists (n=20) and patients with LBP (n=20) for patient involvement in decision making and information provision revealed that the paternalistic style of decision making appeared to dominate physiotherapy practice in Saudi Arabia. However, patients showed a tendency to prefer participation in decision making. Both patients and physiotherapists showed a strong desire for information exchange/provision during clinical encounters. These findings indicated the feasibility of exploring preferences in larger numbers, aiming to measure the level of congruence between the two populations.

Testing a questionnaire is as integral part of its validating process (Bowling, 2009). The primary aim of the pilot study was to test the face and content validity of the questionnaires to be used in the main study. The testing procedure involved

examining the structure and domains of each questionnaire and testing items for relevance, acceptability, sequence and wording by piloting them with physiotherapists and patients with LBP in Saudi Arabia. The exploratory interviews showed that the participants found the questionnaire items to be highly relevant, clear and acceptable. The amendments presented in Tables xxx and xxx involved rewording, omitting and changing the order of items. However, an extensive revision of the items after piloting revealed further changes, mainly in section three on the most recent experience. These changes were made to reduce the number of words and make the items in this section more direct and straightforward, as suggested by participants.

Although the patients' questionnaire was translated into formal Arabic, patients were able to understand its items and reflect on them. Simple formal Arabic is the standard language for all Arab nations and is easily understood by ordinary Saudis, but it would not have been appropriate to translate the patients' questionnaire into any of the dialects of Arabic spoken in Saudi Arabia, since these differ from each other and cannot be easily understood by the general population. The pilot study proved that physiotherapists found it appropriate to use English to give their responses.

When recruiting participants for this pilot study, the researcher found that people were not familiar with research work, so she had to give extensive explanations and spend a considerable time in recruiting patients. Cultural considerations within Saudi Arabia seemed to be the reason for most patients and three of the physiotherapists preferring not to be recorded during their interviews. It was also noticed that male patients tended not to welcome the one-to-one interview with the researcher, because of similar considerations. The piloting of this questionnaire in Saudi Arabia indicated that cultural and social considerations needed to be acknowledged in designing methods for the current research (Oppenheim, 1992, Boynton et al., 2004, Boynton and Greenhalgh, 2004). Analysis of the demographic data showed that the study sample was varied and thus likely to be representative (Boynton, 2004).

The final draft of physiotherapist and patient questionnaires that were used for the purpose of the current research study are presented in Appendix 4.9 and 4.10.

Chapter Five

Study 1: Patients' preferences for involvement in decision making and information gathering in the management of non-specific low back pain

5.1 Introduction

This chapter reports a study on preferences of patients with non-specific LBP for participation in decision making and information gathering, sets out its aims, methods and results. These are then discussed in detail and brief conclusions drawn. Justifications concerning the design of this study, the sampling procedure and selection of the sites are presented in chapter three.

5.2 Aims

The principal aim of **'Study One'** is to explore the preferences of patients with non-specific LBP for participation in making decisions and gathering information when managing LBP within physiotherapy settings in Saudi Arabia. Specific aims of the current study as well as the objectives are the following:

Aim 1

To identify and examine patient preferences for participation in decision making to manage their non-specific LBP.

Objectives: to

1. examine three levels of preferences of participants; these are:

- General preferences for participation in decision making.
- Preferences for participation in making decisions regarding specific key aspects of physiotherapy management of patients with non-specific LBP.
- The overarching preference for patient participation in decision making.

2. Identify and examine the degree to which clinical, demographic or psychological factors are associated with patients' preferences for participation in decision making.

Aim 2

To identify and examine participants' preferences for information gathering or receiving on aspects of the therapeutic process.

Objectives: to

Identify and examine the degree to which clinical, demographic or psychological factors are associated with participants' preferences for gathering or receiving information.

Aim 3

To examine the association between participants' pre-management preferences and their perceived experiences during a recent physiotherapy course.

Objectives: to

- examine factors associated with participants' perceived experiences during a recent physiotherapy course.
- examine, compare and contrast participants' pre-management preferences for patient participation in decision making and their perceived experiences.
- examine, compare and contrast participants' pre-management preferences for information receiving and their perceived experiences.

Aim 4

- to examine participants' level of satisfaction with decisions made and information received to manage their LBP during a recent physiotherapy course.

Objectives: to

- identify and examine the degree to which clinical, demographic or psychological factors are associated participants' level of satisfaction.

Aim 5

To examine the theoretical construction of the study questionnaires in relation to the conceptually distinct areas identified in chapter two and four of the current thesis.

Objectives:

- To identify factors in the questionnaires and examine whether the number of items could be reduced and better focused in future studies.

5.3 Method

5.3.1 Study design

A cross-sectional, paper-based self-completion questionnaire was administered to patients with LBP in two parts and at two time points. Data collection for this phase took place over six months between December 2009 and May 2010.

5.3.2 Participants

From the twenty-six hospitals that met study selection criteria across the three cities of Riyadh, Jeddah and Dammam, twelve were randomly selected to recruit participants for the current study, of which eleven agreed to participate: seven in Riyadh and two each in Dammam and Jeddah. Two of the hospitals were private and nine public, of which five were civilian and four military.

All patients with LBP who were receiving physiotherapy treatment for their LBP from the outpatient services on the selected sites during the study period were approached and invited to participate, subject to the following criteria.

Inclusion criteria

Participants were invited to participate if they were female or male adults, aged 18 years and above and referred to physiotherapy out-patient services with non-specific LBP with or without nerve root involvement (Koes et al., 2006). Participants also had to be able to read and write in Arabic (Hay et al., 2008), to ensure that they could reveal their preferences by completing the questionnaire unaided, thus minimizing the potential influence of other persons not involved in the study.

Exclusion criteria

Participants were excluded if their LBP was associated with a specific condition, such as tumour, fracture, infection or cauda equina syndrome (Fritz et al., 2003, Hay et al., 2008).

5.3.3 Ethical approval

The current study was approved by the Research Ethics Committee at King's College London (BDM/08/09-28); see Appendix 5.1. In addition, local approval and agreement were obtained from the hospitals involved; see CD Appendix 3 for exemplars.

5.3.4 Procedure

5.3.4.1 Recruitment procedure

- **Study Sites**

Selected hospitals were approached by contacting the heads of physiotherapy departments in their offices, by telephone, by fax and/or by email. Invitation letters (Appendix 11 of the attached CD) were sent by fax to all heads of physiotherapy departments, attached to information sheets (CD Appendix 2) setting out the study aims and procedures. Department heads were asked to agree to and cooperate with the conduct of the research study within their institutions. A preliminary visit was conducted to each physiotherapy department, with permission from its head. The aim of these visits was to explain the study procedure to heads of department, clinical supervisors, staff physiotherapists and reception staff.

- **Participants**

Participating patients were identified with the cooperation of physiotherapists delivering outpatient physiotherapy services in the selected hospitals, who were asked to decide on the eligibility of their LBP patients to participate in the study. The researcher explained to the physiotherapists the selection criteria for the study, which comprised only items that would normally be included in all physiotherapy assessments for patients with low back pain and which therefore did not require the therapists to undertake extra assessments.

5.3.4.2 Study procedure

The procedure to explore participants' preferences was carried out in two stages; the questionnaire was split into two corresponding parts in order to examine the similarities and differences between patients' preferred level of involvement and their experience during treatment.

Stage 1

The first stage involved distributing part one of the questionnaire; including two sections on examining pre-management preferences for decision making and information provision; in addition to items on demographic characteristics, a body chart and other baseline questions associated with features of their LBP (see chapter four for details). The LBP baseline section comprised the Hospital Anxiety and Depression Scale (HADS), the Modified Roland Morris Disability Questionnaire (RMDQ) and the Numerical Pain Scale (NPS). These were all handed to each potential participant at the beginning of their course of physiotherapy treatment. Part one of the questionnaire; in addition to the other materials on baseline information about patients were presented together in a single booklet and patients were asked to complete them, place them in an envelope provided for the purpose and then return the envelopes, sealed, to the reception staff.

Stage 2

The second stage was designed to collect data on participants' perceived experiences of participation in decision making and information gathering, in addition to their level of satisfaction with treatment decisions made and information gathered during their physiotherapy course. This was gathered using the last two sections of the questionnaire (part two), which participants were given shortly before their discharge from physiotherapy services. Reception staff handed it to them upon receiving a note from the treating physiotherapists indicating their eligibility. Patients were asked to complete the second part if they chose to continue to participate.

- **Questionnaire distribution**

Each department was provided with packages of invitation letters, questionnaires and information sheets, in sealed envelopes, to be handed to potential participants. The

researcher was in regular and frequent telephone contact with reception staff, physiotherapists and managers of the departments involved. She also made regular visits to these departments, visiting hospitals in Riyadh weekly and those in the other two cities once every three weeks.

All members of the reception staff of physiotherapy out-patients services had training sessions with the researcher about the aims of the study, the recruitment procedure and the study procedure, to enable them to provide the necessary information to potential participants. They were asked to approach these patients, to explain the aim and procedures to them and to hand them the packs of information sheets and questionnaires to complete.

Physiotherapists were provided with marking sheets enabling them to identify eligible participants. These sheets were in two parts, representing the two stages of the study as detailed above. Physiotherapists were asked to tick the relevant box on each sheet to specify whether a patient was eligible or not. If so, the patient was asked to take the sheet to the reception staff, who would then invite them to participate. At the end of part one of the main questionnaire, a note was posted on reception desks to remind/invite patients to participate in stage two of the study. Potential participants were informed about what participation would entail and how to volunteer. Patients were able to discuss the study's aims and procedures, as well as their potential participation, with their families or friends. They were also able to contact the research student through the contact information provided in the last section of the information sheets if they wished to ask her any questions.

5.4 Data analysis

Statistical analysis of the questionnaire data (see chapter three for details and justifications) was carried out using SPSS for Windows (version 19), as follows:

- **Testing for homogeneity of variance**: The one-way ANOVA was used for homogeneity (the Brown-Forsythe statistics) of those who completed the two parts of the questionnaire and those who completed part one only (see chapter three; page 64 for details).

- **Missing data:** details on dealing with missing data are provided in page 64.

- **Descriptive analysis** was performed in terms of frequencies, proportions and cross-tabulations for the responses obtained. In addition, means and standard deviations were calculated for levels of pain, anxiety, depression and disability. Participants' demographic characteristics were presented in proportions.

- **Univariate analysis:** Chi-square tests, namely the Pearson chi-square and Fisher exact tests, were used to identify associations and differences within groups of participants in relation to their demographic characteristics and variables associated with their LBP baseline data (Field, 2000). All tests were conducted with a significance level of 5% (see justifications on selecting the significance level in chapter three). The p-values are presented when the associations of participants' clinical, demographic and psychological characteristics with their responses are found significant. For clarity, only significant results are shown in the presented results, while tables showing non-significant values are presented in CD Appendix 12. In addition, tables demonstrating proportions explains the significant associations of the clinical, demographic and psychological factors with participants responses are all presented in tables in CD Appendix 13, based on results from the univariate analysis.

- **Multivariate analysis:** ordinal logistic regression modelling was used to examine the associations and interactions between a subset of independent variables (explanatory variables) with regard to their effects on selected outcome variables (questionnaire's items). Justifications on selecting particular variables to enter the model are provided in chapter three.

- **Exploratory factor analysis (EFA)**: EFA was carried out with an oblique rotation where loadings less than 0.45 are removed. The variables were load onto the factor analysis. The correlation matrix was created and then items were selected using a variable reduction technique (Tabachnick and Fidell, 2013). Factors that were identified with less than three variables were discarded, and a variable that is loaded onto more than one factor is excluded (Tabachnick and

Fidell, 2013). A conceptual description (an overarching title) was given to each factor.

5.5 Results

This section presents firstly the number of completed questionnaires returned, participants' characteristics and LBP baseline data. Secondly, it provides descriptive and inference analysis to addressing study aims and objectives.

5.5.1 Number of completed questionnaires returned

A total of **775** questionnaires were distributed as follows: **475** in Riyadh and **150** each in Dammam and Jeddah. It is not possible to determine the true response rate, since the number of questionnaires distributed by members of reception staff and physiotherapists to potential participants is not known (see chapter three for justifications). A total of **296** completed 'part one' of the questionnaires, while **178** completed the two parts (see chapter four for more details on splitting the patient questionnaire into two parts). Table **5.1** presents the total number of the returned questionnaires in each involved city. All data sets derived from returned questionnaires were used in the analysis for this study.

Table 5.1: Number of returned questionnaires

City of Kingdom	Part one only	Two parts of the questionnaire
Riyadh	170	103
Jeddah	57	36
Damam	69	39
Total	296	189

The One-Way ANOVA for homogeneity, of those who completed the two parts of the questionnaire and those who completed part one only, revealed no significant differences between the two groups in terms of their clinical, demographics and psychological characteristics; except for pain level before physiotherapy course ($p=.025$) and pain location ($p <.001$). Pain level was higher in those who completed both parts and extended pain (involves thigh, knee or foot) were also more in those who completed both parts.

5.5.2 Participants' characteristics

Data on participants' characteristics in numbers and proportions of responses are presented in Table 5.2. Participants' ages ranged from 18 to 57 years and there were slightly fewer males than females. A minority were postgraduates and a few were unemployed, retired or students. Participants living in villas accounted for more than half of the sample. Almost half of participants received their physiotherapy treatment in military hospitals and a similar number were treated in civilian public sector hospitals, whereas a small minority received their physiotherapy in the private sector.

Table 5.2 : Participants' demographic characteristics

Characteristic	Number of responses	Percentage %
Age (years)		
18-24	37	13
25-34	63	21
35-44	67	23
45-54	66	22
55- more	63	21
Gender		
Male	133	45
Female	162	55
Educational Level		
Primary	59	21
Intermediate/secondary	91	32
College/University	99	35
Postgraduate	26	9
Other	13	5
Occupational Status		
Unemployed	23	8
Manual Work	26	9
Housewife	88	30
Professional	92	32
Student	26	9
Retired	36	12
Current Housing		
Villa	161	55
Semi-villa/flat	105	36
Mud/traditional house	28	10
Hospital Type		
Military	137	46
Ministry of Health	83	28
University	52	18
Private	24	8

5.5.3 Low back pain baseline information

The baseline information collected on LBP were patient self-report assessments of pain location, pain intensity and disability level (Dionne et al., 2008). Anxiety and depression levels (Elrufaie and Absood, 1987, Bener et al., 2006) were also measured. Mean and standard deviations of the observed scores (Foster et al., 2008a, Christoph, 1997) on these features are presented in Table 5.3, while frequencies and proportions are presented in Table 5.4. It was found that pain intensity was mostly moderate and that a large majority of participants reported centralized back pain. The highest level of disability reported by participants was a score of 21 on the RMDQ and the lowest was 1. About half of participants showed low levels of anxiety and depression on the HADS (scoring between 1 and 7), while around a third were moderately anxious (scoring between 12 and 15) and mildly depressed (scoring between 8 and 11).

Table 5.3: Means and standard deviations for characteristics of LBP reported by participants at baseline: pain, disability and anxiety/depression

Characteristics of LBP	Total number of responses	Mean of observed scores	Standard deviation
Pain: Numerical Pain Scale (NPS) (0-10)	258	6.23	2.3
Disability: RMDQ score	267	13.9	5.3
Anxiety and depression: total HADS	231	15.6	7.8
Anxiety: HADS anxiety score (HADA)	231	7.92	4.2
Depression: HADS depression score (HADD)	231	7.52	3.9

Table 5.4: Number and percentage of participants reporting LBP baseline information

LBP baseline features	Total number of responses	Number and percentage of participants reporting LBP baseline information			
Pain location	253	**Pain centralised** 200 (80%)	**Pain extending to the thigh** 18 (7%)	**Pain extending to the knee** 19 (7%)	**Pain extending to the foot** 16 (6%)
Pain (NPS) (0-10)	259	**No Pain/ Normal** 0 1 (.4%)	**Mild 1-3** 35 (14%)	**Moderate 4-6** 147 (57%)	**Severe 8-10** 76 (29%)
Disability (RMDQ) (0-21)	265	**No disability/ Normal** 0 0	**Mild 1-7** 33 (13%)	**Moderate 8-14** 107 (40%)	**Severe 15-21** 125 (47%)
Anxiety (HADA) (1-20)	231	**Normal 1-7** 113 (49%)	**Mild 8-11** 46 (20%)	**Moderate 12-15** 64 (28%)	**Severe 16-18** 8 (3%)
Depression (HADD) (1-20)	231	**Normal 1-7** 116 (50%)	**Mild 8-11** 63 (27%)	**Moderate 12-15** 47 (21%)	**Severe 16-20** 5 (2%)

NPS: Numerical Pain Scale**; RMDQ:** Ronald-Morris Disability Questionnaire**; HADA & HADD:** Anxiety and depression scores on the Hospital Anxiety and Depression Scale

5.5.4 Participants' preferences for patient participation in decision making and associated factors

This section, in three subsections, addresses '**Aim 1**' of the current study and its related objectives.

5.5.4.1 Participants' general preferences for participation in decision making and associated factors

This subsection presents participants' general preferences for participation in decision making; in addition to factors associated with it. Items concerning these preferences are presented in Table 5.5.

Table 5.5: Items addressing general preferences for participation in decision making

Question Number	Item
1	The important management decisions should be made by the physiotherapist, not me.
2	I should decide how frequently I should be seen by my physiotherapist.
3	Patients in physiotherapy departments should not make decisions about their own physiotherapy care.
4	I should decide whether I need a follow-up physiotherapy appointment.
5	I should go along with the physiotherapist's advice even if I disagree with it.
6	I should feel free to make decisions about my physiotherapy management.
7	My views should be taken into account in the discharge plan
8	I should normally participate with my physiotherapist in making decisions about my LBP management.

Participants' general views of their preferred decisional roles are presented as proportions in Figure 5.1 and as frequencies and proportions in Table 5.6. Colour coding is used to indicate preferred roles (green = passive; purple = neutral; orange = active). A general tendency was observed for participants to prefer a passive role in the making of important treatment decisions, while they mostly preferred an active role when making decisions on discharge plans and how frequently they should be seen by their physiotherapists. They also showed a preference for active participation in making physiotherapy decisions and believed that they should feel free to make decisions concerning their physiotherapy management.

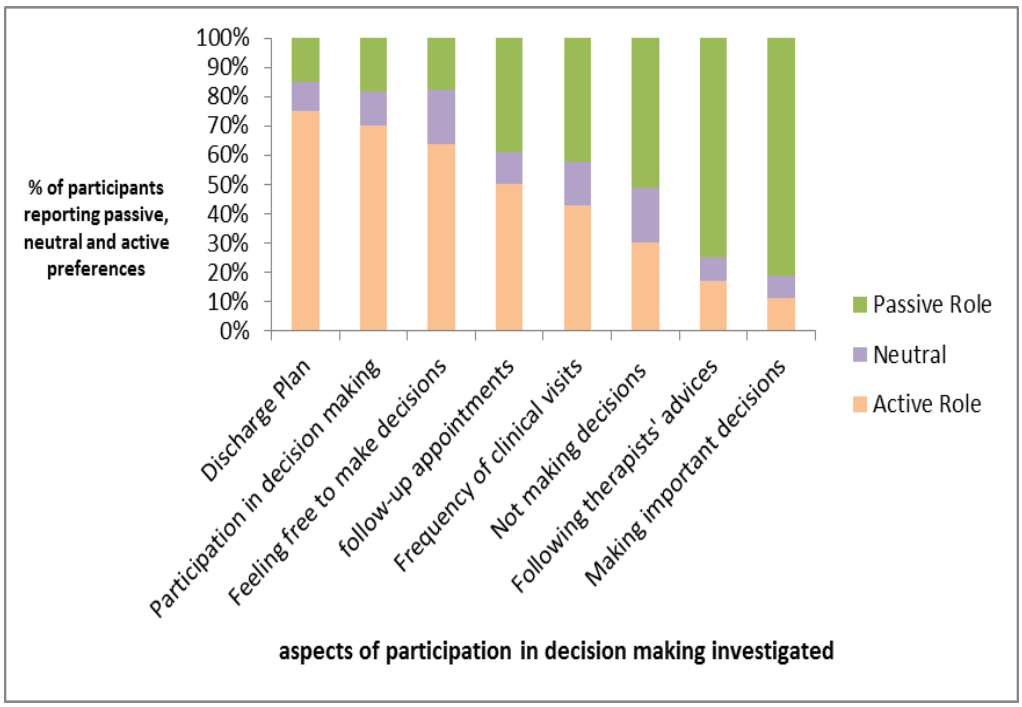

Figure 5.1: Proportions of participants reporting passive, neutral or active general preferences for participation in decision making

Table 5.6: Proportions of participants reporting general preferences for passive, neutral or active participation in decision making

General views of decision making	Total number of responses	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Making important decisions	296	6 (2%)	26 (9%)	24 (8%)	133 (45%)	107 (36%)
		Very active	Active	Neutral	Passive	Very Passive
Not making decisions	292	27 (9%)	62 (21%)	54 (19%)	107 (37%)	42 (14%)
		Very active	Active	Neutral	Passive	Very Passive
Patients feel free to make decisions	291	14 (5%)	37 (13%)	54 (19%)	141 (49%)	45 (16%)
		Very Passive	Passive	Neutral	Active	Very active
Patients normally participate in making decisions	294	11 (4%)	42 (14%)	34 (12%)	133 (45%)	74 (25%)
		Very Passive	Passive	Neutral	Active	Very Active
Frequency of clinical visits	289	29 (10%)	92 (32%)	43 (15%)	95 (33%)	30 (10%)
		Very Passive	Passive	Neutral	Active	Very active
Follow-up appointments	289	28 (10%)	82 (29%)	33 (11%)	122 (42%)	24 (8%)
		Very Passive	Passive	Neutral	Active	Very Active
Going along with therapists' advice	290	10 (3%)	39 (14%)	22 (8%)	145 (50%)	74 (26%)
		Very active	Active	Neutral	Passive	Very Passive
The discharge plan	291	7 (3%)	36 (12%)	30 (10%)	147 (51%)	71 (24%)
		Very Passive	Passive	Neutral	Active	Very Active

Key: Participants' preferred roles in decision making are coloured **orange** for active or very active, **green** for passive or very passive and **purple** for neutral.

- **The associations of participants' clinical, demographic and psychological characteristics with their general preferences for participation in decision making**

p-values of the Chi-square tests for the associations of participants' clinical, demographic and psychological characteristics with their general preferences for participation in decision making are presented in Table 5.7.

Table 5.7: p-values of the Chi-square tests on the associations of participants' clinical, demographic and psychological characteristics to their general preferences for participation in decision making

General preferences for decision making	Age	Highest education level	Hospital type	Pain level (NPS)	Pain location (body chart)	Disability level (RMDQ)	Anxiety level (HADA)	Depression level (HADD)
Making important decisions	.002	.027		.021				.016
Not making decisions	.001		.017			.034		.010
Feeling free to make decisions	.001	.006		.048			.046	
Normally participate in making decisions	.002		.009				.026	
Frequency of clinical visits	.018							
Follow-up appointments			.007	.030				
Going along with therapists' advice			.000		.044	.046		
Discharge plan	.005		.027				.006	.039

Blank Cells: Non-significant at 5% level

The following results report differences in participants' reported preferences; indicating the associations of their demographic characteristics and features of their LBP with their preferences for participation in decision making in general (see table 5.5 for the questionnaire items).

- **General statements concerning whether patients should participate in physiotherapy decision making**

1. **Making important management decisions:**

While there was a general tendency for participants to prefer a passive role in making important decisions about their physiotherapy management, younger (chi: 12.009, df:

2, p<0.002) and more educated participants (chi: 14.3, df: 6, p=0.027) preferred an active role compared to the other groups of participants. In addition, participants with no or mild pain (chi: 11.6, df:4, p=0.021), or mild depression (chi: 8.2, df: 2, p=.016) were found to prefer a more active role in making important decisions (Table 1: CD Appendix 13).

2. **Not making decisions about physiotherapy:**

Older (chi: 22.3, df: 4, p<0.001), and those treated in Ministry of Health (MOH) and university hospitals (chi:15.39, df:6, p= 0.017) preferred a more passive role. In general, by contrast, participants who were less disabled (chi: 6.73, df:2, p=0.034), less depressed (Fisher's exact test: 7.3, df: 1, p=.010) and received their physiotherapy at military hospitals (chi:15.39, df:6, p=0.017) preferred a more active role (Table 2: CD Appendix 13).

3. **Feeling free to make management decisions:**

A general preference towards more active roles regarding participants' feeling free to make decisions about their physiotherapy management was observed. However, participants who were younger (chi: 26.7, df: 4, p=0.001), more educated (chi: 23.1, df:9, p<.006) or had moderate to severe pain (chi: 6.08, df: 2, p=0.048) or moderate to severe depression (chi: 7.9, df: 3, p=0.048) preferred more passive roles (Table 3: CD Appendix 13).

4. **Participation in decision making:**

This was found significantly associated with participants' age, level of anxiety and hospital type. In general, participants preferred a more active role in making decisions about their LBP management. The active role was generally the preference of participants who were younger (chi: 14.3, df:3, p<.002) or received their physiotherapy in military or university hospitals (chi: 17.02, df: 6, p<.009) and of those who were normal or had a mild level of anxiety (chi: 9.3, df: 3, p= .026) (Table 4: CD Appendix 13).

- **Participants' general views on whether patients should participate in making specific clinical decisions**

1. Frequency of physiotherapy visits:

This was found significantly associated with participants' age. Older participants preferred a more passive role compared to younger participants (chi: 11.98, df: 4, sig=0.018) (Table 5: CD Appendix 13).

2. Follow-up physiotherapy appointments:

This was found significantly associated with hospital type and pain level. Participants who were treated in university hospitals had no specific preferences towards either role, whereas participants who received their physiotherapy in military hospitals preferred a more active role compared to those who were treated in MOH and private hospitals (chi: 14.1, df:4, p< =0.007) (Table 6: CD Appendix 13).

3. Following physiotherapists' advice:

Differences in responses as to whether patients should go along with the physiotherapist's advice even if they disagree with it were found associated with hospital type, pain level and location, and levels of anxiety and depression. Participants who were treated in private hospitals had no specific preferences for either role, while those who were treated in university hospitals preferred a more active role compared to those treated in other types of hospital (chi: 35.07, df: 6, p<0.001). Participants who had more pain preferred a more passive role (chi: 6.9, df: 2, p=.030). Those who had peripheral pain (chi: 6.3, df: 2, p=0.044), severe disability (chi: 9.7, df: 4, p=0.046) or who had normal or mild anxiety (chi: 7.9, df: 3, p=.046) also preferred a more passive role compared to others (Table 7: CD Appendix 13).

4. The discharge plan:

This was found significantly associated with age, hospital type and levels of anxiety and depression. The active role was preferred by most, while those who were older (chi: 12.8, df: 3, p<0.005), received their treatment in MOH or private hospitals (chi: 14.3, df:6, p=0.027) or had moderate to severe anxiety (chi: 12.3, df: 3, P<.006) or

depression (Fisher's exact test: 4.9, df: 1, p=.039) preferred a more passive role (Table 8: CD Appendix 13).

- **Associations and interactions between the explanatory variables identified in Chi-square tests**

The above highlighted outcome variables; in addition to the explanatory variables (factors) that were found significantly associated with it have been explored for potential interactions using ordinal logistic regression. Results of the multivariate analysis revealed that among a number of explanatory factors (age, education level, Hospital type, pain level, pain location and levels of disability, anxiety and depression), differences in participants' general preferences for patient participation in decision making were found most explained by their age then by pain level and finally by hospital type (only one outcome variable for each). Table 5.8 presents the 'Parameter Estimates' of participants' age, pain level and hospital type in association with the outcome variables; using the 'Backward Elimination Technique' (see chapter three for details).

Table 5.8 : Results of Tests of Model effect and 'Parameter Estimates' of factors' interactions in association with participants' general preferences for participation in decision making

The Outcome Variable/s	The explanatory variable/s	Estimate	Std. Error	df	p-value
Making important management decisions	Participants' age	.871	.367	1	.018
	Pain level	-1.712	.488	1	.016
Not making decisions about physiotherapy	Participants' age	-.940	.234	1	.001
Feeling free to make management decisions	Participants' age	.979	.234	1	.001
Participation in decision making	Participants' age	.738	.255	1	.004
Frequency of physiotherapy visits	Participants' age	.785	.228	1	.001
Follow-up physiotherapy appointments	Hospital type	-1.099	.510	1	.031

Std. Error: Standard Error; **df**: degree of freedom

5.5.4.2 Participants' specific preferences for participation in making decisions about various aspects of the physiotherapeutic process and associated factors

This subsection presents participants' preferences for participation in making decisions about various aspects of the physiotherapeutic process; in addition to factors associated with it. Items concerning these preferences are presented in Table 5.9.

Table 5.9: Preference for participation in making decisions on specific aspects of the therapeutic process

Question Number	Item
9	Whether I should change/adjust my routine daily activities.
10	When I am ready to carry out my routine daily activities.
11	What type of treatment I should receive in the physiotherapy department.
12	Whether I should follow a home management programme following my visit to the physiotherapy department.
13	How frequently I should be seen by my physiotherapist.
14	How much supervision I need during physiotherapy treatment sessions.
15	When a more senior physiotherapist should be consulted about my LBP management.
16	Whether I need to be referred back to my treating physician.
17	When I should be discharged from physiotherapy services.

Participants' preferences for participation in making decisions about specific aspects of the therapeutic process are presented in proportions in Figure 5.2 below and as frequencies and proportions in Table 5.10. Preferences are classified into three categories: decisions to be made predominantly by the patient (orange), shared equally with the therapist (purple) or predominantly by the therapist (green).

In general, leaving management decisions to be made or controlled by physiotherapists was the participants' dominant preference. However, they preferred to have an active role in making decisions associated with their home programmes and daily activities. They also preferred a more sharing role when decisions associated with the frequency of physiotherapy visits and to discharge from physiotherapy

services. Having a role in making decisions about what type of treatment they should receive was their least preferred option.

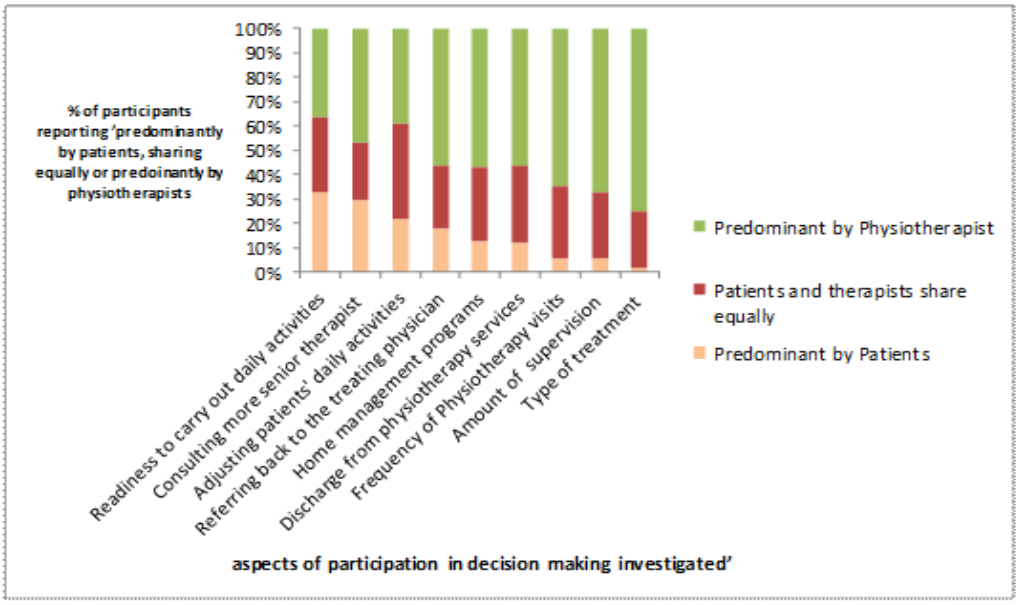

Figure 5.2: Proportions of participants reporting passive, neutral or active general preference for participation in decision making

Table 5.10: Numbers and proportions of participants reporting passive, neutral or active preferences for participation in decision making

Aspects of physiotherapy decisions	Total number of responses	Patient alone	Mostly patient	Therapist and patient equally	Therapist alone	Mostly therapist
		Predominantly by patient		Sharing equally	Predominantly by therapist	
Changing/adjusting routine daily activities	**288**	38 (13%)	26 (9%)	112 (39%)	42 (15%)	70 (24%)
Readiness to carry out routine activities	**285**	39 (14%)	55 (19%)	88 (31%)	48 (17%)	55 (19%)
Home management programmes	**281**	14 (5%)	21 (8%)	83 (30%)	67 (24%)	96 (34%)
Type of physiotherapy treatment	**291**	7 (2%)	0 (0%)	67 (23%)	124 (43%)	93 (32%)
Frequency of physiotherapy visits	**283**	9 (3%)	8 (3%)	83 (30%)	102 (36%)	81 (29%)
Amount of supervision	**288**	7 (2%)	10 (4%)	76 (27%)	101 (35%)	94 (33%)
Consulting a more senior physiotherapist	**282**	37 (13%)	47 (17%)	67 (24%)	66 (24%)	65 (23%)
Referring back to the treating physician	**285**	28 (10%)	23 (8%)	74 (26%)	88 (31%)	72 (25%)
Discharge from physiotherapy services	**287**	21 (7%)	13 (5%)	90 (32%)	99 (35%)	64 (22%)

- **The associations of participants' clinical, demographic and psychological characteristics with their preferences for participation in making decisions about various aspects of the therapeutic process**

p-values of the Chi-square tests for the associations of participants' clinical, demographic and psychological characteristics with their preferences for participation in making decisions about various aspects of the therapeutic process are presented in Table 5.11.

Table 5.11: p-values of the Chi-square tests on the associations of participants' clinical, demographic and psychological characteristics with their preferences for participation in making decisions about various aspects of the therapeutic process

Aspects of physiotherapy decisions	Age (years)	Gender	Pain Location (body chart)	Disability Level (RMDQ)	Anxiety level (HADA)	Depression level (HADD)
Changing/adjusting patients' routine daily activities	.008	.031	.044			.003
Readiness to carry out routine daily activities	.000	.046				.013
Type of treatment patients should receive	.002		.003		.001	.050
Frequency of physiotherapy visits	.018			.022		
Consulting a more senior physiotherapist				.011		.004
Referring back to the treating physician	.030				.020	.034
Discharge from physiotherapy services	.001					

Blank Cells: Non-significant at 5% level

The following results report differences in participants' reported preferences; indicating the associations of their demographic characteristics and features of their LBP to their preferences for participation in making decisions about various aspects of the therapeutic process (see table 5.9 for the questionnaire items).

- **Participants' preferences for who should decide on their self-management**

This involved making decisions on adjusting daily activities and readiness to carry out routine activities.

1. Changing/adjusting routine daily activities:

Differences among participants' preferences were observed according to their age, education, level of depression, pain location and house type. Participants who were younger (chi: 15.5, df: 4, p<0.004), female (chi: 10.6, df: 4, p=0.031), less educated (chi: 16.04, df: 6, p=0.014), normal or less depressed (chi: 8.7, df: 3, p=.033) and those who had centralized pain (Fisher's exact test: 12.07, df: 2, p<0.002) preferred an active role (Table 9: CD Appendix 13).

2. Readiness to carry out routine daily activities:

Participants' age, gender, hospital type and depression level were found significantly associated with their preference for deciding on their readiness to carry out their daily activities. Participants who were younger (chi: 20.5, df: 4, p<0.001), female (chi: 9.7, df: 4, p=.046), being treated in university or military hospitals (chi: 19.4, df: 8, p=0.013) or less depressed (chi: 12.3, df: 4, p=.013) preferred to share the responsibility (Table 10: CD Appendix 13).

- **Patients' preferences for who should decide about decisions concerns clinical situations**

These involved making decisions within physiotherapy settings as following:

1. Frequency of physiotherapy visits:

This was significantly associated with participants' age and disability level. Although both age groups showed a preference for these to be made by their physiotherapists, younger participants (chi: 10.06, df: 3, p=0.018) preferred them to be shared equally with the therapist. This sharing role was also preferred by participants who were normal or had mild disability (Fisher's exact test: 10.9, df: 4, p<0.022) (Table 11: CD Appendix 13).

2. Type of treatment:

Age, pain location and levels of anxiety and depression were found significantly associated with participants' preferences for type of treatment. Although a clear majority of participants preferred decisions about type of treatment to be made by their physiotherapists, a preference for sharing the responsibility equally was observed in those who were younger (chi: 14.9, df: 3, p<.002), had back pain (Fisher's exact test: 11.3, df:2, p<.003), were normal or had mild anxiety (Fisher's exact test: 16.1, df: 3,

p<.001) or mild depression (Fisher's exact test: 7.4, df: 3, p=.050) (Table 12: CD Appendix 13).

3. Consulting a more senior physiotherapist:

Patients with moderate or severe disability mostly preferred to share this decision with the therapist (chi: 16.6, df: 6, p=0.011), while those who were more depressed preferred it to be made predominantly by the physiotherapist (chi: 15.5, df: 4, p=.004) (Table 13: CD Appendix 13).

4. Referring patients back to the treating physician:

Older participants preferred this decision to be made predominantly by the physiotherapist (chi: 10.7, df: 4, p=0.030), as did those who were more depressed (chi: 8.7, df: 3, p=.034) (Table 14: CD Appendix 13).

5. The discharge plan:

Most preferred such decisions to be made by the therapist, but younger participants (chi: 17.6, df: 4, p< 0.001) and those who were less depressed (chi:7.7, df: 3, p= .053) preferred to share this role (Table 15: CD Appendix 13).

- **Associations and interactions between the explanatory variables identified in Chi-square tests**

Based on the results revealed by the univariate analysis (see above in Table 5.11) the outcome and explanatory variables were selected to enter the ordinal regression model.

As shown in Table 5.11 above, preferences in this section were significantly associated with participants' age. However, results of the multivariate ordinal regression modelling revealed that participants' specific preferences for patient participation in making decisions about various aspects of the physiotherapeutic process showed that in addition to age, pain location and levels of anxiety, depression and disability significantly explained preferences for patient participation in making decisions about the following: 1) type of treatment; 2) frequency of clinical visits; and 3) whether a patient should be referred back to the treating physician. Table 5.12 presents the 'Parameter Estimates' of the identified explanatory factors in association with the outcome variables; using the 'Backward Elimination Technique'.

Table 5.12 : Results of Tests of Model effect and 'Parameter Estimates' of factors' interactions in association with participants' specific preferences for participation making decisions about various aspects of the physiotherapeutic process

The Outcome Variable/s	The explanatory variable/s	Estimate	Std. Error	df	p-value
Type of treatment patients should receive	Participants' age	-.697	.312	1	.030
	Pain location	1.124	.470	1	.017
Frequency of physiotherapy visits	Disability level	1.039	.401	1	.009
Referring back to the treating physician	Anxiety level	-1.449	.688	1	.035
	Depression level	1.762	.862	1	.041

Std. Error: Standard Error; **df**: degree of freedom

5.5.4.3 Participants' overarching preference for patient participation in decision making and associated factors

This section addresses the last part of **'Aim 1'** of the current study; identifying and examining patients' overarching preference for participation in decision making. The identified preferences are presented in Table 5.13. Approximately one third of the participants preferred to share this responsibility equally with the physiotherapist, while half of participants preferred to leave such decisions either completely or partly to the physiotherapist.

Table 5.13: Participants' overarching preference for participation in decision making

Participants' preferences	Number of responses	Patients make the decision	Patients make the final decision	Patients and physiotherapists share equally	Physiotherapists make the final decision	Patients leave all decisions to physiotherapists
	289	21 **(7%)**	22 **(8%)**	98 **(34%)**	75 **(26%)**	73 **(25%)**

- **<u>The associations of participants' clinical, demographic and psychological characteristics with their overarching preference for participation in decision making</u>**

A significant association was observed between pain location and participants' age to their overarching preference for participation in decision making. Those who were older (chi: 16.5, df: 3, p=0.012) or had peripheral back pain preferred clinical decisions to be made predominantly by physiotherapists (chi: 9.2, df: 3, p=0.026).

Among all of the explanatory factors, ordinal regression modelling confirms that participants' age and pain location significantly explain participants' overarching preference for participation in decision making. Table 5.14 presents the 'Parameter Estimates' of these identified explanatory factors in association with the outcome variables using the 'Backward Elimination Technique'.

Table 5.14 : Results of Tests of Model effect and 'Parameter Estimates' of factors' interactions in association with participants' overarching preference participation making decisions

The Outcome Variable/s	The explanatory variable/s	Estimate	Std. Error	df	p-value
The overarching preference for participation in decision making	Participants' age	-.641	.249	1	.010
	Pain location	.785	.305	1	.010

Std. Error: Standard Error; **df**: degree of freedom

5.5.5 Participants' preferences for information gathering/receiving on specific aspects of the therapeutic process

This section addresses '**Aim 2**' of the current study 'identifying and examining participants' preferences for information gathering/receiving on specific aspects of the therapeutic processes, and the association of participants' clinical, demographic and psychological factors with these preferences'. Participants were asked to report their preferences in response to the items listed in Table 5.15.

Table 5.15: Questions addressing preferences for information gathering/receiving on specific aspects of the therapeutic process

Question Number	Item
19	I should be given information only when I ask for it.
20	Informing patients is an essential part of any physiotherapy management of LBP.
21	I should have a good understanding of my LBP.
22	If the level of my back pain changes, I should be given more information about what is happening to my back.
23	If the news about my back pain is bad, I should be fully informed.
24	Physiotherapists should explain the purpose of any physiotherapy clinical examinations that they use when assessing of my LBP.
25	When there is more than one method to treat my LBP, I should be informed about each one.
26	It is important for me to know all the possible adverse effects of any physiotherapy interventions used to manage my back pain.

The proportion of participants who expressed preferences for receiving information, expressed as weak, strong and neutral desires, are presented in Figure 5.3, while Table 5.16 gives frequencies and proportions for extent of agreement with the statements listed above. In general, participants reported a strong desire to receive information about managing their LBP. A strong majority reported that informing patients was an essential part of physiotherapy management. They also reported a preference to be given information even if they had not asked for it. Most reported a desire to have a good understanding of their LBP condition and to receive information about the purpose of any clinical examinations, the adverse effects of any treatment modality, 'if the level of their back pain changed', 'if news about their back pain was bad', and 'when there was more than one method to treat their LBP'.

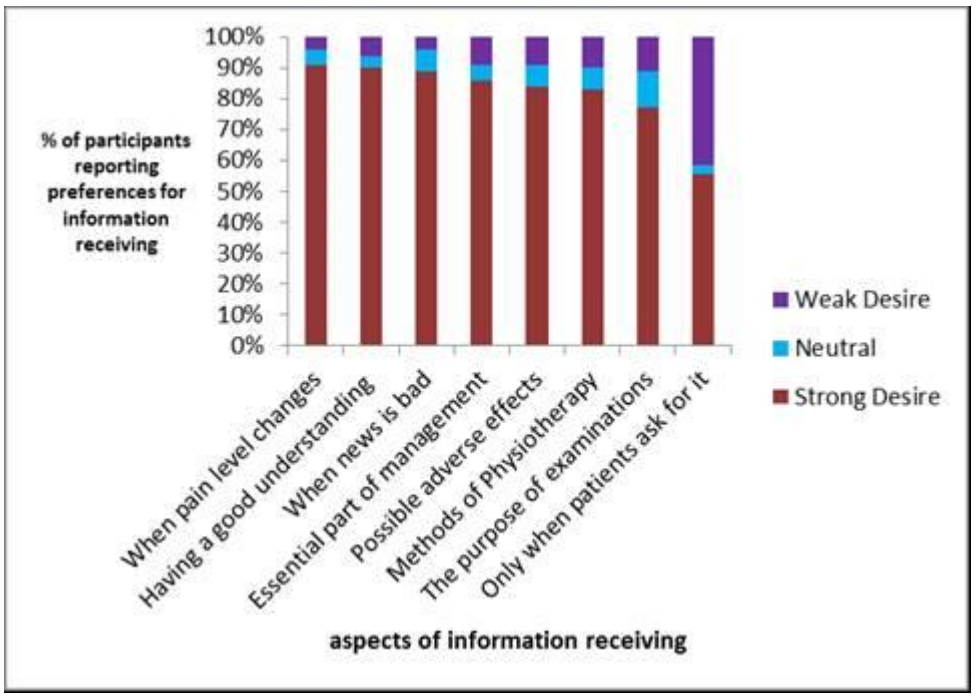

Figure 5.3: Proportions of participants reporting preferences for receiving information on specific aspects of the therapeutic process

Table 5.16: Proportions of participants reporting preferences for receiving information on specific aspects of the therapeutic process

Aspects of information receiving	Total number of responses	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Receiving information only when patients ask for it	287	86 (30%)	74 (26%)	9 (3%)	79 (28%)	39 (14%)
		56% Stronger Desire		3% Neutral	42% Weaker Desire	
Information is essential part of any physiotherapy management	291	1 (.3%)	23 (8%)	15 (5%)	97 (33%)	155 (53%)
		9% Weaker Desire		5% Neutral	86% Stronger Desire	
Having a good understanding of LBP	291	3 (1%)	14 (5%)	12 (4%)	107 (37%)	155 (53%)
		6% Weaker Desire		4% Neutral	90% Stronger Desire	
Receiving information if pain level changes	289	1 (.3%)	12 (4%)	14 (5%)	104 (36%)	158 (55%)
		4% Weaker Desire		5% Neutral	91% Stronger Desire	
Receiving information if the news is bad	289	2 (1%)	10 (3%)	19 (7%)	113 (39%)	145 (50%)
		4% Weaker Desire		7% Neutral	89% Stronger Desire	
Explaining the purpose of any clinical examinations	290	4 (1%)	29 (10%)	34 (12%)	108 (37%)	115 (40%)
		11% Weaker Desire		12% Neutral	77% Stronger Desire	
Methods of physiotherapy to manage LBP	290	2 (1%)	28 (9%)	19 (7%)	119 (40%)	123 (42%)
		10% Weaker Desire		7% Neutral	82% Stronger Desire	
Information about possible adverse effects	291	2 (1%)	24 (8%)	19 (7%)	97 (33%)	149 (51%)
		9% Weaker Desire		7% Neutral	84% Stronger Desire	

Key: Participants' preferences in association with information receiving indicated: **Maroon**: a strong desire, **purple**: a weak desire, **blue**: neutrality.

The associations of participants' clinical, demographic and psychological characteristics with their general preferences for participation in decision making

p-values of the Chi-square tests for the associations of participants' clinical, demographic and psychological characteristics with their preferences for information receiving or gathering about various aspects of the therapeutic process are presented in Table 5.17.

Table 5.17: p-values of the Chi-square tests on the associations of participants' clinical, demographic and psychological characteristics with their preferences for information gathering

Aspects of information receiving	Age	Gender	Highest education level	Pain Level (NPS)	Disability Level (RMDQ)	Anxiety level (HADA)	Depression level (HADD)
Only when patients ask for information	.001			.027			.013
Essential part of any physiotherapy management	.001		.008			.001	.001
Having a good understanding of LBP							.034
If the news is bad		.031					
The purpose of examinations	.014						
Methods of physiotherapy to manage LBP	.018			.046	.022	.037	.019
Possible adverse effects	.012	.038			.041	.001	

Blank Cells: Non-significant at 5% level

- **The associations of participants' clinical, demographic and psychological characteristics with their general preferences for information receiving or gathering**

Based on the univariate analysis, the following results illustrate differences in participants' reported preferences, indicating the association of their demographic characteristics and features of their LBP with their preferences for information gathering/receiving on specific clinical aspects of the therapeutic process (see table 5.15 for the questionnaire items).

- **Patients' reported preferences for receiving information, in general.**

- **Receiving information only when patients ask for it:**

A strong desire to receive information only when they asked for it was mostly noticed in patients who were younger (chi: 16.6, df: 3, p=0.001), had less pain (chi: 14.3, df: 6, p=0.027) or were less depressed (chi: 8.6, df: 2, p=.013) (Table 16: CD Appendix 13).

- **Information is an essential part of any physiotherapy management:**

Participants were less likely to agree that receiving of information is an essential part of physiotherapy management if they were older (chi: 16.8, df: 3, p=0.001), more educated (chi: 17.4, df: 6, p=.008), more anxious (chi: 13.8, df: 2, p=.001) or more depressed (chi: 15.1, df: 2, p=001) (Table 17: CD Appendix 13).

- **Patient having a good understanding of LBP:**

While a majority of participants agreed that they should have this understanding, those who were less likely to agree were those who were more depressed (chi: 8.3, df: 2, p=.016) (Table 18: CD Appendix 13).

- **Receiving information if the news is bad**:

Female participants (chi: 8.8, df: 3, p=0.031) reported a stronger desire to receive information in such circumstances (Table 19: CD Appendix 13).

- **Participants' reported preferences for receiving information about specific clinical aspects of the therapeutic process.**

- **Receiving explanations of physiotherapy examinations:**

A stronger desire to receive information about the purpose of clinical examinations was found in younger participants (chi: 10.6, df: 3, p=0.014) (Table 20: CD Appendix 13).

- **Receiving information about physiotherapy methods to manage LBP:**

Weaker preferences for information about different methods of treating LBP were observed when participants were older (chi: 10.06, df: 3, p=0.018), had moderate pain level (chi: 9.7, df: 4, p=0.046), moderate disability (chi: 11.5, df: 4, p= 0.022) or moderate to severe anxiety (chi: 6.6, df: 2, p=.037) or depression (chi: 7.9, df: 2, p=.019) (Table 21: CD Appendix 13).

- **Receiving information about possible adverse effects:**

Older patients (chi: 10.9, df: 3, p= 0.012), males (chi: 8.4, df: 3, p=0.038) and those who were moderately disabled (chi: 9.9, df: 4, p=0.041) or severely depressed (chi: 16.1, df: 3, p=.001) had a weaker desire for such information (Table 22: CD Appendix 13).

- **Associations and interactions between the explanatory variables identified in Chi-square tests**

Based on the results revealed by the univariate analysis (see above in Table 5.17) the outcome and explanatory variables were selected to enter the ordinal regression model.

The ordinal regression modelling shows that participants' age and pain location significantly explain preferences for the overall attitude to participation in decision making. These types of preferences were most explained by participants' age. Table 5.18 presents the 'Parameter Estimates' of the identified explanatory factors in association with the outcome variables, using the 'Backward Elimination Technique'.

Table 5.18 : Results of Tests of Model effect and 'Parameter Estimates' of factors' interactions in association with participants' preferences for information receiving/gathering on specific aspects of the physiotherapeutic process

The Outcome Variable/s	The explanatory variable/s	Estimate	Std. Error	df	p-value
Receiving information only when patients ask for information	Participants' age	-.836	.241	1	.001
Information is essential part of any physiotherapy management	Participants' age	-1.323	.468	1	.005
	Education level	-1.039	.337	1	.002
	Depression level	2.458	.986	1	.013
Receiving information if the news is bad	Gender	-1.239	.428	1	.004
Explaining the purpose of examinations	Patients' age	.538	.297	1	.034
Receiving information methods of physiotherapy to manage LBP	Patients' age	.301	.320	1	.012
Receiving information about possible adverse effects	Patients' age	-.1.025	.385	1	.004
	Disability level	-.914	.387	1	.016

Std. Error: Standard Error; **df**: degree of freedom

5.5.6 The association between patients' pre-management preferences and their perceived experiences during a recent physiotherapy course

This section addresses '**Aim 3**' of the current study 'examining the association between participants' pre-management preferences and their perceived experiences during a recent physiotherapy course'. Participants were asked to report their perceived experiences in response to the questions listed in Table 5.19 below.

Table 5.19: Questions addressing participants' perceived experience of their involvement in making decisions and receiving information during their current course of physiotherapy

Question Number	Question
27	How much did you participate in the decision making process?
28	How much information did you gather from your physiotherapist about your LBP?
29	Do you think that the severity of your pain affected how much you wanted to be involved in the decisions made?
30	How much did your physiotherapist encourage you to participate in making decisions about the management of your LBP?
31	How much did your physiotherapist encourage you to gather the information you wanted from her/him about your LBP and its management?
32	What type/s of information did you receive during your physiotherapy course?

Objective 1: to

- to identify participants' perceived experiences during their current course of physiotherapy and examine factors associated with it.

Participants' reported experiences of decisional roles and receiving information are presented in Table 5.20. The results show that in general, patients more often received information than were involved in making treatment decisions. This included participants' perceptions of their physiotherapists' level of encouragement. In addition, the majority of participants thought that severity of pain level had not influenced their preferences for involvement in making decisions about their physiotherapy care.

Table: 5.20: Proportions of participants' reported experience of their involvement in decision making and information receiving during their current course of physiotherapy treatment

Patients' reported experience of their current course of physiotherapy treatment	Total number of responses	Not at all	A little	A fair amount	A lot	A great deal
Participating in making decisions	176	14 (8%)	37 (21%)	53 (30%)	57 (32%)	15 (9%)
Information gathered from the physiotherapist	177	4 (2%)	31 (18%)	53 (30%)	54 (31%)	35 (20%)
Whether the severity of pain affected patients' desire to be involved in making decisions	171	39 (23%)	35 (21%)	47 (28%)	37 (22%)	13 (8%)
Physiotherapists' encouragement of patients to participate in making treatment decisions	176	8 (5%)	29 (17%)	43 (24%)	52 (30%)	44 (25%)
Physiotherapists' encouragement of patients to gather clinical information	177	9 (5%)	27 (15%)	44 (25%)	50 (29%)	

Table 5.21 shows the types of clinical information received by patients during their physiotherapy. Participants reported having received more information about self-management programmes, general information about LBP and preventive management strategies, whereas less information was received about spine biomechanics/ healthy posture and common physiotherapy management of LBP. In the 'other' category, participants reported receiving information about various types of therapeutic exercise.

Table 5.21: Reported type/s of clinical information received by participants during their current course of physiotherapy treatment

Reported type/s of information received	Number of responses 171	Percentage
Back pain in general	66	39%
Spine biomechanics and healthy posture	44	26%
Pain behaviour & management	61	36%
Self-management programmes	114	67%
Preventive management strategies	109	64%
Common physiotherapy management for LBP	46	27%

- **The associations of participants' clinical, demographic and psychological characteristics with their perceived experiences during their current course of physiotherapy treatment**

The following results indicate differences in participants' reported experiences of their involvement in making decisions and receiving information during their current course of physiotherapy treatment, in addition to the types of information received (see Table 5.19 for questions).

- **Participants' reported experiences of participation in decision making during their current course of physiotherapy treatment**

Patients who reported more participation in the decision making process were those who had no or had mild disability (chi: 10.9, df: 4, p= 0,027). Those who lived in Dammam (chi: 16.1, df: 4, p=.003) and received their treatment in university hospitals (chi: 16.5, df: 4, p=.020) reported less encouragement by their physiotherapists to

participate in making decisions about their LBP management. In addition, patients who thought that the severity of their pain affected how much they wanted to be involved in making decisions were more likely to have been treated in Jeddah (chi: 12.5, df: 4, p=.014).

- **Participants' reported experiences of participation in gathering information during their current course of physiotherapy treatment**

  Participants were more likely to report gathering information from physiotherapists about their LBP if they were more educated (Fisher's exact test: 12.9, df: 6, p=.041) or had peripheral pain (chi: 9.1, df: 3, p=.027). Participants who reported being less encouraged to gather information were those who lived in Jeddah (chi: 12.3, df: 4, p=.015), received their treatment in university hospitals (chi: 16.5, df: 4, p=.002) or had moderate to severe pain (Fisher's exact test: 9.44, df: 4, p=.045).

- **Associations and interactions between the explanatory variables identified in Chi-square tests**

  Table 5.22 shows the results of using the ordinal regression model to explain participants' perceived experiences with participation in decision making and information gathering during a physiotherapy treatment course. Participants' disability and pain levels were the only explanatory variables with significant results.

Table 5.22 : Results of Tests of Model effect and 'Parameter Estimates' of factors' interactions in relation to participants' perceived experiences with participation in decision making and information gathering during physiotherapy course

The Outcome Variable/s	The explanatory variable/s	Estimate	Std. Error	df	p-value.
Perceived experiences with participation in decision making	Disability level	1.292	.463	1	.005
Perceived experiences with information gathering/receiving	Disability level	.903	.421	1	.032
	Pain level	.962	.447	1	.031

Std. Error: Standard Error; **df**: degree of freedom

Objectives 2 and 3:

In order to examine, compare and contrast participants' pre-management preferences for patient participation in decision making and information receiving, and their perceived experiences, two questions were selected from each part of the questionnaire (Table 5.23) These particular questions were selected as they reflect a general sense of preferences as well as experiences with physiotherapy care.

Table 5.23: Questions generally addressing participants' pre-management preferences and perceived experiences of their involvement during their current course of physiotherapy

Number	Question
18	In general, which statement describes your overall attitude to participation in making-decisions about physiotherapy management for your LBP?
21	I should have a good understanding of my LBP.
29	How much did you participate in the decision making process?
30	How much information did you gather from your physiotherapist about your LBP?

Results revealed by the Chi-square test (Linear-Linear Association) showed no significant association between participants' pre-management preferences and their perceived experiences with participation in decision making and information gathering during physiotherapy care.

5.5.7 Participants' satisfaction with decisions made and information received during their physiotherapy care and factors associated with their satisfaction

This section addresses '**Aim 4**'of the current study; concerning patients' satisfaction with decisions made and information received during their current course of physiotherapy treatment, and factors associated with their satisfaction. Participants were asked to report their satisfaction in response to the items listed in Table 5.24.

Table 5.24: Items addressing participants' satisfaction with decisions made and information received during their current course of physiotherapy treatment

Question Number	Item
33	I am very satisfied with the physiotherapy I received.
34	There are things about the physiotherapy I received that could have been better.
35	I was satisfied with how decisions were made.
36	I was satisfied with the information I was given about my back pain.

Participants' reported satisfaction with the decisions made and with the information they received during physiotherapy care for their LBP is presented in Table 5.25. In general, a high level of satisfaction was reported, although a number of participants stated that certain aspects could have been better. No significant association was observed between patients' reported satisfaction and their demographic characteristics or the features of their LBP.

Table 5.25: Participants' reported satisfaction with their current course of physiotherapy treatment

Aspects of satisfaction reported by patients	Total number of responses	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Satisfaction with the physiotherapy received	159	6 (4%)	13 (8%)	17 (11%)	87 (55%)	36 (23%)
Physiotherapy care could have been better	155	12 (8%)	33 (21%)	39 (25%)	52 (34%)	19 (12%)
Satisfaction with how decisions were made	157	5 (3%)	10 (6%)	24 (15%)	95 (61%)	23 (15%)
Satisfaction with the information given	160	5 (3%)	9 (6%)	25 (16%)	82 (51%)	39 (24%)

- **Associations and interactions between the explanatory variables identified in Chi-square tests**

The ordinal regression modelling revealed that levels of disability and depression were significantly associated with participants' level of satisfaction with decisions made about their physiotherapy care; while level of depression was found significantly associated with participants' satisfaction with information received Table 5.26 presents these associations.

Table 5.26 : Results of Tests of Model effect and 'Parameter Estimates' of factors' interactions in association with participants' level of satisfaction with decisions made and information received during physiotherapy course

The Outcome Variable/s	The explanatory variable/s	Estimate	Std. Error	df	p-value.
Participants' level of satisfaction with decisions made	Disability level	2.379	.356	1	.029
	Depression level	-16.545	.436	1	.001
Participants' level of satisfaction with information received	Depression level	-16.30	.469	1	.001

Std. Error: Standard Error; **df**: degree of freedom

5.5.8 Results of factor analysis

Eigenvalues (4.560, 2.559, 2.942 and 1.704) in addition to the percentages of variance explained (14.636, 22.77, 32.26 and 37.99) suggested extracting four factors. Therefore, four factors were produced along the line of the items. No overlapping was observed between items allocated in the produced factors. However, a number of items (presented in Table 5.27) were removed from the matrix since the factor loading was less than 0.45. The rest of the variables were loaded onto four factors. These are presented in Table 5.28. Therefore, the questionnaire items were reduced to 24 items. Although the items were loaded to same categories (factors) of the original structure of the questionnaires, two factors loaded differently; these are: 'My views should be taken into account in the discharge plan' (was originally under the general views and loaded under information) and 'When a more senior physiotherapist should be consulted about my LBP management' (was originally under specific views on participation in decision making and loaded under the general views).

Table 5.27: Items removed from the correlation matrix

I should decide how frequently I should be seen by my physiotherapist
If the news about my back pain is bad, I should be fully informed
I should be given information only when I ask for it
I should feel free to make decisions about my physiotherapy management
do you think that the severity of your pain affected how much you wanted to be involved in the decisions made?
In general, which statement best describes your overarching preference participation in making-decisions about physiotherapy management for your LBP
I should go along with the physiotherapist's advice even if I disagree with it

Table 5.28: Factor analysis of questions to look at loading and redundancy

Items	Factor			
	1	2	3	4
	Info	Exp.	Role	indep
When there is more than one method to treat my LBP, I should be informed about each one	.963			
Informing patients is an essential part of any physiotherapy management for LBP	.879			
It is important for me to know all the possible adverse effects of any physiotherapy interventions used to manage my back pain	.739			
Physiotherapists should explain the purpose of any physiotherapy clinical examinations that they use when assessing of my LBP	.720			
If the level of my back pain changes, I should be given more information about what is happening to my back	.584			
My views should be taken into account in the discharge plan	.562			
I should normally participate with my physiotherapists in making decisions about my LBP management				-.454
I should have a good understanding of my LBP	.436			
How much did your physiotherapist encourage you to participate in making decisions about the management of your LBP?		.836		
How much did your physiotherapist encourage you to gather information you wanted from her/him about you LBP and its management?		.808		
How much information did You gather from your physiotherapist about your LBP?		.724		
How much did you participate in the decision-making process?		.717		
How frequently I should be seen by my physiotherapist			.657	
When I should be discharged from physiotherapy services			.645	
How much supervision I need during physiotherapy treatment sessions			.603	
Whether I need to be referred back to my treating physician			.536	
What type of treatment I should receive in the physiotherapy department			.514	
Whether I should change/adjust my routine daily activities			.471	
When a more senior physiotherapist should be consulted about my LBP management				.055
Whether I should do a home management program following my visit to the physiotherapy department			.457	
When I am ready to carry out my routine daily activities			.455	
The important management decisions should be made by the physiotherapist, not me				.628
I should decide whether I need a follow-up physiotherapy appointment				.512
Patients in physiotherapy departments should not make decisions about their own physiotherapy care				-.465

Info: information; Exp: experience; Role: decisional role; indep: independency

5.6 Discussion

The current study examined patients' preferences for involvement in decision making, their preferences with respect to receiving information, and their experiences of and level of satisfaction with the physiotherapeutic management of their LBP. This section

summarises and discusses the main findings of the study, compares the results to the relevant literature, concerns methodological critique, and presents implications of this study for physiotherapy practice.

5.6.1 Summary and general discussion of main findings

- **Number of returned questionnaires**

The One-Way ANOVA for homogeneity, of those who completed the two parts of the questionnaire and those who completed part one only, revealed significant differences between the two groups in their pain level before physiotherapy course and pain location. However, this analysis revealed no significant differences in 'HAD' and disability scores or in participants' demographics. Therefore, the observed variations in pain level can be attributed to the subjective examination and the possibility that pain experience can be over/under reported by patients with LBP (Peolsson et al., 2000). In addition, magnetic resonance imaging scans identified no association between neuropathic pain and presence or absence of nerve root compression, supporting the importance of clinical tests to examine possible neuropathic pain (Beith et al., 2011). It was established that patients' reporting of their pain location and pain level is less likely to determine the severity of their LBP condition in isolation of the other clinical and psychological features. However, these two factors, in addition to other factors were included in the statistical analysis as factors/co-variances in order to examine their potential associations with patients' preferences. Based on the above, no further examinations were undertaken to examine differences in preferences between those who completed the two parts of the questionnaire and those who completed part one only, since the ANOVA results support that the two groups were essentially homogenous; thus the full dataset was used in the analysis of participants' preferences.

- **Participants' characteristics**

Despite the large sample surveyed, it was dominated in demographic terms by older participants who had been educated to intermediate/secondary school or college level, by housewives and professionals, by people who lived in villas or flats/semi-villas and by those who received their physiotherapy in military or MOH hospitals. Current

results were consistent with the findings of a Saudi community survey by Al-Arfaj and colleagues (2003), as both studies showed that in Saudi Arabia as elsewhere, the prevalence of back pain increases with age. However, these authors reported a higher prevalence among females, possibly because their study was conducted in primary care settings, where patients often attend for a single visit by self-referring, while patients have no direct access to physiotherapy department and their physiotherapy course may require multiple visits. No information available from Saudi Arabia indicates differences in numbers and characteristics of patients with LBP who attend physiotherapy departments and primary care settings.

Study participants mostly presented with centralized and moderate back pain, high disability due to LBP and low to moderate anxiety and depression levels. It appears therefore that those who responded to this survey were those who are less severely affected and further studies will need to target those with greater severity (Dionne et al., 2008). A study set in Saudi Arabia and others in the neighbouring United Arab Emirates show high associations between LBP and psychological manifestations such as depression and anxiety (Al-Arfaj et al., 2003, Bener et al., 2004, Bener et al., 2006) and again our survey is biased towards the less affected.

- **Factor analysis**

The items of two questionnaires were conceptually related at the stage of developing and testing these questionnaires (see chapter four). The questionnaire was designed to cover pre-management preferences (involve three areas) and the perceived experiences/practices of 'patient involvement. These areas emerge from two main domains that construct the questionnaires in relation to 'patient involvement'; these are: 1) patient participation in decision making; and 2) information provision. The pre-management preferences involve examining patient participation in decision making in two sides; general and specific ones. while general preferences were designed to examine participants' general views that are not related to certain clinical scenarios, the specific preferences for patient participation in decision making concerned identifying the preferred decisional role 'Who should make the decision' on a number of clinical aspects of managing patients with LBP. Based on this description as well as

results revealed in the pilot studies, it was anticipated that the questionnaire items are theoretically correlated.

Exploratory factor analysis (EFA) has produced four factors that were consistent with the original construction of the questionnaire which grouped the items into four distinct areas. This confirms the initial hypothesis related to the theoretical construction of the questionnaire and proved that the majority of the questionnaire items have the ability to hold together; matching with the original theoretical construction. This also suggests that sections on decision making and information can be used independently to examine participants' preferences. EFA will assist reducing the questionnaire items. Although EFA was useful to remove redundant items; still a confirmatory factor analysis is required to examine theory to allocating items onto pre-specified factors (Tabachnick and Fidell, 2013).

- **Preferences for participation in decision making and information provision**

In the current study, patients' preferences for their participation in decision making were examined in three areas of preferences in the physiotherapeutic context: 1) patients' general views of being involved in making decisions about their physiotherapy management of their LBP; 2) preferences for participation in making specific clinical decisions; and 3) their overarching preference as to 'who should make the decision' when managing their LBP.

Current findings indicate that patients' preferences regarding these three areas varied. A preference for a more active role was observed when patients were asked about general and non-specific situations, but this preference was reduced when they were asked about decisions related to specific clinical situations or when stating who should make the overall decision about their physiotherapy care. This suggests that preferences may be influenced by the situation in which participants find themselves under higher responsibility that often felt in real-life contexts or increased sense of risk due to illness (Müller-Engelmann et al., 2011). Using interviews or questionnaire surveys with various population sizes and medical conditions, several studies reported that preferences may vary according to the nature of decisions, the severity of medical conditions, patients' clinical knowledge and features of therapeutic options

(Thompson et al., 1993, Adams et al., 2001, Müller-Engelmann et al., 2011). Levinson and colleagues (2005) conducted a large general social survey and found that participants wanted to be offered treatment choices but preferred to leave the final decision to their treating physicians. In the current study, 19% of participants gave a neutral response when asked whether they should or should not feel free to make decisions about their own physiotherapy care. This may indicate the low level of knowledge and awareness, or uncertainty among participants about their roles in making clinical decisions.

Preferences for a more active role ranged between 2% and 33%, depending on the specific situation. The highest proportions were observed in response to items concerning decisions about participants' home management programmes and daily activities. This suggests that participants wanted more control of their LBP condition in the familiar, 'home' setting, outside the clinical setting. In addition, 30% wanted a more active role in consulting a more senior physiotherapist. However, patients most often preferred these decisions to be shared with their physiotherapists. Participants wanting to feel free about consulting another physiotherapist may indicate their anxiousness (perhaps due to LBP) or being dissatisfied with decisions that are made about their physiotherapy care.

In terms of therapeutic aspects in which decision making occurred, preferences for deciding about number of clinical visits and follow up appointments were least influenced by participants' demographic characteristics, and most strongly influenced for whether patients should be involved in making important decisions about their physiotherapy care, not making decisions, feeling free to make decisions and deciding about the discharge plan. This raises the possibility that the more general the statement about participation, the more likely it was that mixed opinions were observed.

Preferences with respect to information giving and receiving differed slightly to those for taking part in decision making. Among the study sample, about 10% of patients reported a weak desire to receive information about physiotherapy treatment options to manage their LBP; most expressed a stronger desire for clinical information than

participation in decision making. Participants reported a stronger desire for information when pain level changed, but a weaker desire for information about the purpose of clinical examinations. It is possible that anxiety associated with LBP led to this strong desire to know more when pain changes. It is also possible that patients' lack of knowledge about physiotherapeutic approaches to managing LBP contributed to their choice of a passive decisional role regarding treatment options. However, emotional distress associated with LBP is more likely to negatively affect patients' understanding of clinical processes and decisions that are being made about managing their condition (O'connor, 1995). Participants may have thought that they did not need to know details of clinical examinations and that this was a professional skill outside their remit. In addition, participants' desires to receive information about methods of physiotherapy to manage LBP were found associated with levels of pain, disability, anxiety and depression. These findings support an association between patients' desire for clinical information and the severity of their illness. It is also possible that patients' lack of knowledge about physiotherapeutic approaches to managing their LBP contributed to their choice of a passive decisional role regarding treatment options. Further work was necessary to explore this and some information derived from the focus groups is discussed later in chapter nine.

5.6.2 Discussion of main findings in relation to the literature

While introducing a number of novel aspects, this study differs from those reported in the literature in three key respects.

- most other studies were conducted outside clinical physiotherapy settings and no other studies were conducted in a similar cultural setting.
- Few studies distinguished preferences in relation to general preferences, preferences about specific decisions and preferences about who should make the overarching decision.
- There is considerable variation in the design and outcome measures used in other studies, making direct comparison difficult.

Despite this, the results tend in general to match those reported elsewhere, providing a strong basis for accepting the validity of the key findings.

The first key area we examined related to preferences for participating in decision making.

Preferences for leaving decisions to be made or controlled predominantly by physiotherapists ranged between 29% and 68%. As this finding was yielded by a structured questionnaire study, it does not provide definite reasons for the participants' passivity. Between 23% and 39% of participants preferred the sharing role, lower than diabetic patients (n=134) as confirmed by Sekimoto and colleagues (2004), who studied the preferences of at a single outpatient clinic in Japan, using face to face interviews. This supports the evidence (Fernandez and Turk, 1989, Keefe et al., 1990, Jensen et al., 1991, Folkman and Moskowitz, 2004) that LBP sufferers tend to rely on others to relieve their pain as a passive coping strategy. In addition, it is likely that the cultural differences between the two settings will be a major factor – one that would need further exploration.

Analysis of the overarching preference for 'who should make the decision' in the present study shows that just over half of participants (51%) preferred decisions to be either made or controlled by physiotherapists, whereas almost a third of the sample preferred a sharing role (34%). This is in line with the results of other studies; between 52% and 60% in asthma (Adams et al., 2001) and cardiac problems (Burton et al., 2010), and patients with numerous medical conditions (Levinson et al., 2005, Chang et al., 2008). More recent Western studies show participants want to adopt a sharing role; in hypertension (88%) (Nomura et al., 2007), life-threatening illnesses such as cancer (60%) (Stewart et al., 2000) and a wide range of other health conditions (62% and 77.8%) (Murray et al., 2007, Deber et al., 2007) Although these results appear different from the current findings, they have in common with the current study the feature that patients were not uniform in their preferences. This is again highlights possible influences of variations in clinical contexts, nature of clinical condition and situational circumstances.

As noted in chapter two, identifying which, if any, factors are more important in relation to patients' preferences remains unclear. Robinson and Thomson (2001) suggest that examining preferences based on demographic characteristics may help in predicting those who are most likely to benefit from using decision aids. An earlier suggestion by Beisecker (1988) is that situational circumstances appear more important than demographic variables in predicting patient behaviour towards decisional roles. This indicates that patients may behave differently from their self-perceptions when they interact with their clinicians, due to other environmental factors (Thompson et al., 1993, Bandura, 2001, Müller-Engelmann et al., 2011).

Patient preferences for participation in decision making during physiotherapy sessions was not evaluated, in the current study, and no information was available about any situational circumstances pertaining to the participants' actual care; information was only available about hospital type and severity of LBP. Participants who received their physiotherapy programme at military hospitals were more likely to prefer an active role in decision making. Perhaps this is due to the awareness of patients and clinicians in this situation, since SDM is implemented in these hospitals as policy; however, Bastiaens and colleagues report that variations in the health systems of eleven European countries have not influenced patients' views of their involvement in decision making (Bastiaens et al., 2007). It might also be associated with the type of participants attending these settings; though we found no evidence of this when we compared groups. The numbers from these setting were however small and this may be a methodological issue rather than a strong finding.

Demographic characteristics were associated with differences in patients' reported preferences for decisional roles. In general, these results are consistent with those of previous studies: younger, female, more educated and healthier participants preferred a more active role (Cassileth et al., 1980, Stiggelbout and Kiebert, 1997, Sekimoto et al., 2004, Levinson et al., 2005, Florin, 2006). All of these studies investigated patient preferences for participation in decision making within various medical disciplines. In contrast to the current study, Burton and colleagues (2010) did not find a significant association between patients' demographic characteristics (n=83) and their reported preferences in cardiology settings; it may be that a larger sample would be required to

show such an association. As noted in chapter two of this thesis, there is mixed evidence in the existing literature of the influence of demographic characteristics on patients' preferences for involvement in decision making. The uncertainty over using demographic characteristics as predictors of patient preferences may indicate that these would need to be examined on an individual basis (Bastiaens et al., 2007) as well as in relation to other situational factors (Thompson et al., 1993, Müller-Engelmann et al., 2011).

Age was the most significant demographic variable influencing patients' preferences for participation in decision making similar to many other studies (Thompson et al., 1993, Adams et al., 2001, Robinson and Thomson, 2001, Murray et al., 2007). In this study, older participants preferred a more passive role in decision making , consistent with other studies which report patients over 45 prefer more passive roles (Levinson et al., 2005, Burton et al., 2010). The strong association between participants' preferences and their age may be explained by differences between younger and older patients in levels of readiness and motivation to participate in decision making. This may be attributed in turn to the tendency of older individuals to depend more heavily on clinicians to take care of their health on their behalf, compared to younger people (Nomura et al., 2007, Chang et al., 2008).

Beisecker and colleagues (1988) offer two explanations for this association between age and a preference for a passive decisional role. The first is what they refer to as "role theory", which indicates that older individuals are used to the traditional biomedical model of decision making, where clinicians prefer to adopt a paternalistic style. The second is more "developmental", where the psychosocial aspects of the ageing process are considered to explain why older people prefer to leave the responsibilities of decision making to others. One interesting difference between the two age groups observed by Beisecker (1988) is that older patients tend to be more consistent than younger patients, in terms of their perceptions of and attitudes to their decisional roles. This is possibly because the elderly tend to be more constant in their lifestyles, with limited changes to physical and daily activities.

In the current study, gender had a limited association with participants' preferences for participation in decision making. The only two situations where significant

differences were observed were those related to decisions concerning self-management, where female participants showed a stronger preference for more active and sharing roles. This limited association may be due to differences in clinical tasks about which patients were asked to provide their preferences, rather than differences in gender itself (Florin, 2006). Male participants' preferences for more passive role were similar to those reported in a number of previous studies (Nomura et al., 2007, Asghari et al., 2008), although Stewart et al. (2004) demonstrated that the two genders preferred shared decision making to an equal extent in managing acute ischemic coronary disease. The female participants to preference for more active roles was in line with other studies reported in the literature (Benbassat et al., 1998, Sekimoto et al., 2004, Florin, 2006, Nomura et al., 2007, Chang et al., 2008). However, current evidence suggests that the influence of gender on individuals' preferences for involvement in decision making is debatable (Florin, 2006). Stewart and associates (2004) found that female and male participants showed similar preferences for sharing and active roles. Although females in Saudi Arabia are usually less educated than males and are generally perceived to adopt a more passive role with respect to their health (Mobaraki and Soderfeldt, 2010), this did not make them more passive regarding their preferences for participation in decision making.

An earlier review suggested that although healthy individuals and those who suffer chronic or life-threatening conditions such as cancer do not seek full autonomy in deciding about their health care, nor do they prefer full passive roles (Benbassat et al., 1998). However, some more recent research evidence on patients from a wide variety of conditions suggests that preferences for participation in decision making become less strong as the severity of the medical condition increases (Adams et al., 2001, Robinson and Thomson, 2001, Sekimoto et al., 2004, Deber et al., 2007, Chang et al., 2008, Burton et al., 2010). This suggestion is relevant to the findings of the current study; while LBP is not a life-threatening condition; results still show that participants who were more severely affected by their LBP condition prefer more passive roles.

This preference for a more passive role may be associated with the emotional distress often associated with LBP, as discussed in chapter two. The impairment of thinking and judgement due to the experience of pain and disability may be one of the problems

that patients face when trying to participate in making treatment decisions concerning their illnesses (O'conner, 1995). Adams and colleagues (2001) found a association between preferences for leaving decisions to be made by clinicians and patients' perceptions of being at risk; they showed that a preference for a more passive role was often associated with the increased severity of patients' asthma attacks. Studies of LBP suggest that patients usually try to avoid increasing their pain and thus cope differently with the consequences of their LBP (Foster et al., 2008b, Foster et al., 2010). On the other hand, Janz and colleagues (2004) found no significant association of psychological status, including anxiety and depression, with decisional control; however, a direct association was found at a marginal level between level of self-efficacy and patients' preferred role in decision making.

The association between severity of medical condition and preferences for decisional role may, however, be attributable to the perception that providing a patient with treatment choices entails two positive points: that the clinician has more control over managing the patient's medical condition and that more than one treatment option is available to resolve this medical problem. This type of thinking may reduce the stress associated with the uncertainty of finding a clinical solution.

It has been also speculated that patients who prefer more active participation in decision making may have greater hope of recovery (Cassileth et al., 1980) and may tend to express this hope by being more motivated and enthusiastic than other patients. There is evidence from cardiology research that patients who presented preoperatively with various levels of desire for involvement in decision making showed better emotional and social recovery and improved health outcomes postoperatively (Mahler and Kulik, 1991, Czar and Engler, 1997).

Evidence from the current study establishes the existence of a positive association between anxiety level and patients wishing to make decisions. This study found that lower levels of anxiety and depression were significantly associated with preferences for more active and sharing roles. The influence of anxiety and depression levels may be associated with the complexity of LBP as a disabling condition (Foster et al., 2008b, Foster et al., 2010). The current findings do not explain the association between

making more or less difficult decisions and levels of anxiety and depression. Morris and Royle (1988) suggest that providing patients with a management choice about their surgery may contribute to reducing their anxiety and depression and not providing them with information, since patients know that there is a range of options to help them with their treatment.

The current findings also show that lower levels of pain were significantly associated with a preference to participate actively in making treatment decisions. An earlier study of preferences for acute pain treatment suggested that patients were ready to tolerate pain in exchange for the less adverse effects of certain medications (Gan et al., 2004). In contrast, Hamann and associates found no difference between patients with multiple sclerosis (MS) at the acute and chronic stages regarding their preferences for participation in decision making (Hamann et al., 2007). Although MS is known as a disabling condition that is often associated with psychological complications, the results of Hamann's study were only examined with respect to socio-demographic variables and no information was provided about preferences in relation to patients' disability level or their quality of life.

The second key area we examined was patient's preferences of information giving and receiving, and in general they demonstrated a stronger desire to be involved.

Participants' strong preference for active participation in information gathering is consistent with many earlier studies (Stiggelbout and Kiebert, 1997, Benbassat et al., 1998, Florin, 2006, Nomura et al., 2007, Chang et al., 2008). By contrast, studies in conditions that may be considered more life threatening differ. A study examining preferences of patients with cancer (Czaja et al., 2003) and others who needed invasive medical and surgical procedures found that they wanted more participation in decision making and less information (Mazur and Hickam, 1997, Asghari et al., 2008); this contrasted with a further study with female patients with cancer, wanted more information (Stewart et al., 2000). There is no clear reason at present for this difference.

Although participants' desire for information was stronger than their desire to participate in decision making, 42% of them agreed that patients should not receive

information if they do not ask for it. It is possible that participants thought that they had no right to receive clinical information unless they asked for it, or perhaps they were not used to receiving information from their health practitioners in the first place. They may have been concerned that they might not understand it or be afraid of what might be provided. Unwillingness to receive information when the news is bad has been reported in previous studies (Hack et al., 1994, Kiesler and Auerbach, 2006).

Age again was the demographic variable that most significantly associated with participants' preferences for receiving information: older participants expressed a weaker desire to receive information than the younger group. This weaker desire for information may be explained by reduced intellectual abilities, possible impaired memory and decreased motivation to know or gather more information about their health care (Beisecker, 1988, Diamond et al., 1996, McGilton et al., 2009, Ones et al., 2009). However, other studies have found that older people wished to receive information about their health care as younger people (Chang et al., 2008, Carnes et al., 2008).

An interesting finding of the current study was that education level was not found significantly associated with participants' preferences for receiving information. This may be because all participants were literate and had a good level of education. However, this finding is in contrast with other studies showed that preferences for gathering information are positively associated with increased education level (Nomura et al., 2007, Chang et al., 2008). One exception to this concerns whether informing patients is considered an essential part of any physiotherapy programme. More educated patients were found less likely to agree with this statement, which suggests that more educated individuals may have sources of information other than physiotherapists from which to learn about their LBP condition.

The findings of this study showed no significant influence of gender differences on participants' preferences for information, except that female participants wanted to know more in two situations: when news was bad and in regard to possible adverse effects of the chosen treatment. Previous studies have also indicated that women often want to be better informed (Arora and McHorney, 2000). This may be attributed

to the higher anxiety ratings that women can have compared to men as part of their information-seeking behaviours. Alternatively, Stewart and colleagues, in the context of acute ischemic coronary disease, associated gender influences in preferences with the type of information with patients' need: men wanted information concerning sexual abilities, while women wanted information about the medical condition itself (Stewart et al., 2004).

Level of depression was the predominant variable associated with participants' preferences for receiving information in this study; the current study findings also indicate a negative association between the desire for information and the severity of LBP and its associated psychological complications (anxiety and depression). It is also important to note that some studies suggest that when patients are informed, this may contribute to reducing fear and anxiety caused by uncertainty surrounding the process of clinical decision making and accordingly minimize decisional conflicts (O'conner, 1995), and it may be that patients with LBP should be encouraged to access information for this reason. However, for their part, Czaja and colleagues highlight that the influence of anxiety on patients' preferences for information is mixed (Czaja et al., 2003) and it seems further work is required to clarify the issue.

The third key area we examined related to the match/mismatch between participants' pre-management preferences and their perceived experiences during physiotherapy course.

While most participants reported a strong desire for receiving information when the level of their LBP changed (91%), their reported experience showed that information received from physiotherapists was, in general, greater than their actual participation in decision making. This is similar to findings of a study of patients with various medical problems (McKeown et al., 2002). Although the current findings suggest a match between desired and gathered information, it is unclear whether the amount of information that participants received was regarded as adequate and whether it was found to match their needs. The findings show that patients were encouraged and were able to gather information from their physiotherapists. This may relate mostly to physiotherapists' perceptions and their willingness to give information to their patients

about managing LBP, since the level of encouragement did not match with participants' desire for information.

In contrast, no association was found between participants' preferences and experiences of participation in decision making. This finding suggests that the two roles do not match and is consistent with others studies (Chapple et al., 2003, Janz et al., 2004, Stewart et al., 2004, Florin, 2006, Hack et al., 2006, Burton et al., 2010), but contradictory to the results reported by Murray and colleagues (2007). For instance, the consensus between preferred and actual decisional roles has been studied in patients with breast cancer (n=101) (Janz et al., 2004). Mismatch between the two roles was reported in this study: before consultation, patients (47%) reported a preference for SDM, but then they reported increased responsibility in making the clinical decisions (61%). Patients who took part in this study were all well-educated and this might be a reason for the increased active decisional role that was facilitated by their physicians.

Patients' satisfaction with their involvement in decision making and information provision may inform physiotherapy clinical practice and help with understanding patient adherence to therapeutic plans. Kaplan and colleagues (1996) have suggested that patient participation in decision making and their satisfaction with medical care are not conceptually associated with each other, but the results of a survey study by Hills and Kitchen (2007) in physiotherapy out-patient services showed that the satisfaction of patients with chronic conditions was associated with their expectations and to treatment outcome. This suggests that patient satisfaction can be associated with various factors; hence the present results do not explain whether patients were satisfied with their physiotherapy care because they felt involved in the decision making process, but Janz and colleagues (date) found a positive association between patient satisfaction in women with breast cancer and their perceived active involvement in decision making.

Kiesler and Auerbach (2006) suggest that the mismatch of patients' preferred and experienced roles can lead to poor treatment outcomes which, in turn, can reduce their satisfaction (Kiesler and Auerbach, 2006). Contrary to this suggestion, patients

who took part in the current study were found to be satisfied with physiotherapy care irrespective of the present finding that no association was observed between preferred and experienced roles in decision making.

Although the current findings indicate that patients were satisfied with their physiotherapy care as well as their information gathering and participation in decision making, it is unclear whether these types of observed satisfaction were associated with each other. Ruiz-Moral and colleagues (2006) found that a greater satisfaction was associated with positive patient perception of clinicians' communicative style in primary care encounters, despite their limited participation in decision making. Patients of psychiatry clinics were also found to be satisfied with clinicians' communication behaviour and with not being involved in decision making, leading Goossensen and colleagues (2007) to suggest that no direct association can be found between patients' satisfaction and their involvement in decision making or information provision. This is consistent with the present findings of no association between satisfaction responses, decisions made, information gathered and participants' initial preferences before receiving their physiotherapy treatment. It is possible that patients' lack of awareness of their potential roles in participating in making decisions or gathering information from their clinicians is a reason for being satisfied.

5.6.3 Methodological critique

This cross-sectional study provided good insights into patients' preferences for participation in decision making and information provision. The design allowed a representative population with a good sample size to be reached and wider views to be captured. However, one inclusion criteria to this study was to involve literate participants only. It was thought that including participants' who are unable to read or write would require their families and/or friends to assist them in completing the questionnaires which might have biased the participants' responses. Difficulties occurred at distributing and at collecting the completed questionnaires. Distribution and collection of questionnaires were undertaken through reception staff and physiotherapists who work in the involved hospitals as recommended by the College Ethics Committee to avoid any kind of pressure on participants to take part if they

were invited directly by the researcher. This is likely to have reduced the number of participants who completed the two parts of the questionnaire.

As highlighted, in chapter three, face to face interviews would have been an appropriate approach; however it was more likely to limit the amount of data obtained due to cultural considerations. The advantages of the questionnaire-based approach were that it addressed the research questions, avoided cultural sensitivies and provided standardized responses that could be statistically computed and interpreted. The good return rate reported confirmed that this approach was appropriate; possibly because some participants felt encouraged to express their views in writing rather than saying. However, the method did not allow in depth analysis of why patients with more severe LBP prefer certain decisional roles and why their desire for information was higher than their desire to participate in decision making. Hence, this method was followed and complemented by a qualitative method (focus group studies) to provide in-depth understanding for participants' views on the research topic, reported in chapter nine.

5.6.4 Implications of this study for practice

As noted in chapter two, patient participation in decision making and information is strongly advocated by the relevant literature. To date, evidence from physiotherapy on this type of clinical practice appears limited. One key finding of the current study is that patients wanted more active role when decisions are made about their daily activities; including home programs to manage their LBP. Despite this, patients preferred physiotherapists to have control over management decisions in physiotherapy encounters. These findings are of importance to physiotherapy practice; as patients wanted to be engaged in making decisions about their care; especially when designing home programs or giving therapeutic instructions to patients.

It is also crucial that physiotherapists pay attentions to patients' strong desires to gather information about their LBP condition and its physiotherapy; including information about various approaches to manage LBP within physiotherapy context,

and possible adverse effects of physiotherapy. Delivering clinical information to the patients may require a good communication level between patients and physiotherapists in order to facilitate information exchange between the two parties. However, this study does not provide information on whether patients wanted information to be able to participate in making decisions about their health care. Further implications of this study for physiotherapy practice are presented in chapter seven.

5.6.5 Conclusion

The cross-sectional survey study was successful in examining patients' preferences for participation in decision making and information provision. The study also provided some indications of the factors that are associated with these preferences. The cultural context of this work is discussed in the final chapter; however, further work is essential to explore the gaps in our knowledge identified by this study; including those with lower education levels and increased severity of LBP and to explore preferences in other similar populations both in Arabic counties and in immigrant populations in western settings.

Chapter Six

Study 2: Physiotherapists' preferences for patient involvement in decision making and information provision in the management of non-specific low back pain

6.1 Introduction

This chapter reports a study on preferences of physiotherapists for participation in decision making and information provision when managing patients with non-specific low back pain (LBP), sets out its aims, methods and results. These are then discussed in detail and brief conclusions drawn. Justifications concerning the design of this study, the sampling procedure and selection of the sites are presented in chapter three.

6.2 Aims

The principal aim of **'Study Two'** is to explore the preferences of physiotherapists for patient participation in decision making and information provision when managing patients with non-specific LBP within physiotherapy setting in Saudi Arabia. Specific aims of the current study as well as the objectives are as the following:

Aim 1

To identify and examine participants' preferences for patient participation in decision making to manage their non-specific LBP.

Objectives: to

1. examine three levels of preferences of participants; these are:

- General preferences for patient participation in decision making.
- Preferences for patient participation in making decisions regarding specific key aspects of physiotherapy management of patients with non-specific LBP.
- The overarching preference for patient participation in decision making.

2. identify and examine the degree to which demographic characteristics are associated with physiotherapists' preferences for patient participation in decision making.

Aim 2

to identify and examine participants' preferences for information provision on aspects of the therapeutic process.

Objectives: to

- identify and examine the degree to which demographic characteristics are associated with participants' preferences for receiving or gathering information.

Aim 3

to examine the associations between participants' preferences for patient participation in decision making and information provision and their perceived practices during a recent physiotherapy course.

Objectives: to

- examine factors associated with participants' perceived practice during a recent physiotherapy course.
- examine, compare and contrast participants' preferences for patient participation in decision making and their perceived practice.
- examine, compare and contrast participants' preferences for information provision and their perceived practice.

6.3 Method

6.3.1 Study Design

A cross-sectional, paper-based self-completion questionnaire was administered to physiotherapists treating patients with non-specific LBP in Saudi Arabia. Data collection for this phase took place over six months between December 2009 and May 2010.

6.3.2 Participants

All physiotherapists treating outpatients with non-specific LBP in the selected sites in three major cities of Saudi Arabia (see chapter three), during the study period, were approached and invited to participate.

Selection criteria

Participants were recruited if they had clinical experience in musculoskeletal physiotherapy of at least two years and worked in the Riyadh, Makkah and Eastern regions of Saudi Arabia. They also had to be registered with the Saudi Commission for Health Specialists and to be managing patients with non-specific LBP as part of their routine clinical practice, seeing at least three new patients per week.

6.3.2.1 Study Sites

Fourteen hospitals were randomly selected to recruit participants for the current study, of which twelve agreed to participate: six hospitals in Riyadh and three each in Dammam and Jeddah. Nine of these were governmental hospitals (five civilian and four military), while the other three operated in the private sector. See section 5.3.4.1 in the previous chapter for the recruitment procedure (page 114). See CD Appendix 14 for the invitation letter to heads of departments.

6.3.3 Ethical approval

See section 5.3.3 in the previous chapter (page 114).

6.3.4 Procedure

6.3.4.1 Recruitment procedure

A comprehensive list of physiotherapists working at each site was identified through heads of department and physiotherapists in charge of outpatient services. The researcher approached physiotherapists either in groups or individually and gave them a verbal explanation of the study aims and procedure, as well as copies of the information sheet (CD Appendix 2).

6.3.4.2 Study procedure

Before distributing the study questionnaire at each site, the researcher held a general meeting with staff physiotherapists treating patients with musculoskeletal conditions in order to invite them to participate in the study and to explain its aims and procedures. At the end of each meeting, each potential participant was given an envelope containing an information sheet and a copy of the questionnaire (in English) to complete if they chose to participate. Physiotherapists who agreed to do so were asked to seal the completed questionnaires inside the envelopes provided and to place them in a box provided by the researcher in the physiotherapists' charting area. More details on this procedure are provided in section xx page xxx.

6.4 Data analysis

Descriptive and inferential analysis (Chi-square tests and ordinal regression modelling) were used. Details on data analysis are provided in section 3.5.1 page 64.

The p-values are presented when the associations of participants' clinical, demographic and psychological characteristics with their responses are found significant. For clarity, only significant results are shown in the presented results, while tables showing non-significant values are presented in CD Appendix 15. In addition, tables demonstrating proportions explains the significant associations of the clinical, demographic and psychological factors with participants responses are all presented in tables in Appendix 16, based on results from the univariate analysis.

6.5 Results

6.5.1 Number of completed questionnaires returned

A total of 280 questionnaires were distributed in proportion to the total number of hospitals of each type in each city, as follows: 140 questionnaires in Riyadh, 80 in Dammam and 60 in Jeddah. A total of 93 completed questionnaires were returned: 48 from Riyadh, 27 from Dammam and 18 from Jeddah (see Table 6.1).

Table 6.1: Number of returned questionnaires

City of Kingdom	Number of distributed questionnaires	Number of returned questionnaires
Riyadh	140	48
Jeddah	60	18
Damam	80	27
Total	280	93

6.5.2 Participants' characteristics

Participants' characteristics are presented as proportions in Table 6.2. A large majority of physiotherapists were aged between 24 and 45 years, only 8% being older than 45 years. Male physiotherapists who participated in the current study were slightly more numerous than females. Most participants had a bachelor degree qualification in physiotherapy, were staff physiotherapists and saw more than five new patients with non-specific LBP each week.

Table 6.2: Participants' characteristics and number of responses (n=93)

Participants' characteristics	Number of responses	Proportions of responses
Age (years)		
24-30	32	35
31-35	32	35
36-40	14	15
41-45	7	8
> 45	7	8
Gender		
Male	48	52
Female	45	48
Professional Qualification		
Bachelor Degree	84	90
Professional Master	6	7
Professional Doctorate	3	3
Work Position		
Staff Therapist	57	61
Senior Therapist	24	26
Specialist/Clinical Supervisor	12	13
Average number of new patients /week		
< 3	13	14
3-5	38	41
> 5	42	45

6.5.3 Participants preferences for patient participation in decision making

This section, in three subsections, addresses '**Aim 1**' of the current study and its related objectives.

6.5.3.1 Participants' general preferences for participation in decision making and associated factors

This section addresses objective one of '**Aim 1**' of the current study 'general preferences for participation in decision making'. Items concerning these preferences are presented in Table 6.3. These involved general statements on whether patients should participate in physiotherapy decision making or not.

Table 6.3: Questions addressing general preferences for participation in decision making

Question Number	Questions addressing general preferences for participation in decision making
1	The important management decisions should be made by the physiotherapist, not patients
2	Patients should decide how frequently they should be seen by their physiotherapists.
3	Patients in physiotherapy departments should not make decisions about their own physiotherapy care
4	Patients should decide whether they need a follow-up physiotherapy appointment
5	Patients should go along with the physiotherapist's advice even if they disagree with it
6	Patients should feel free to make decisions about their physiotherapy management
7	Patients' views should be taken into account in the discharge plan
8	Patients should normally participate with physiotherapists in making decisions about the management of their LBP

Participants' general preferences for patient participation in decision making are presented in Table 6.4 and Figure 1.1, using colours to indicate the preferred roles: green indicates passive or very passive, orange means active or very active and purple represents neutral responses to the items (neither agree nor disagree). Most of the participants thought that patients should not make important decisions or feel free to make decisions about their physiotherapy management, but most thought that patients should normally participate with their physiotherapists in making decisions about their LBP management and that patients' views should be taken into account in the discharge plan. Most participants also thought that patients should be passive when decisions were made about the frequency of clinical visits and follow-up

appointments and that patients should go along with the physiotherapist's advice, even when they disagreed with it.

Table: 6.4 Proportions of participants reporting passive, neutral or active roles as general preferences for patient participation in decision making

Aspects of participation in decision making investigated	Total number of responses (n=93)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Making important decisions	92	2 (2%)	7 (8%)	6 (7%)	33 (36%)	44 (47%)
		Very active	Active	Neutral	Passive	Very passive
Not making decisions	92	13 (14%)	26 (28%)	14 (16%)	23 (25%)	16 (17%)
		Very active	Active	Neutral	Passive	Very passive
Patients should feel free to make decisions	92	17 (19%)	24 (26%)	12 (13%)	25 (28%)	13 (14%)
		Very passive	Passive	Neutral	Active	Very active
Patients should normally participate in making decisions	90	7 (8%)	15 (16%)	11 (12%)	40 (44%)	19 (21%)
		Very passive	Passive	Neutral	Active	Very active
Frequency of clinical visits	91	40 (44%)	33 (36%)	7 (8%)	5 (5%)	7 (8%)
		Very passive	Passive	Neutral	Active	Very active
Follow-up appointments	91	33 (37%)	31 (34%	6 (7%)	15 (17%)	5 (6%)
		Very passive	Passive	Neutral	Active	Very active
Going along with therapist's advice	90	8 (9%)	14 (15%)	11 (12%)	34 (37%)	24 (26%)
		Very active	Active	Neutral	Passive	Very passive
The discharge plan	91	2 (2%)	5 (6%)	12 (13%)	49 (54%)	22 (24%)
		Very passive	Passive	Neutral	Active	Very active

Key: Participants' preferences in relation to decision making were **orange** = active or very active, **green** = passive or very passive, **purple** = neutral.

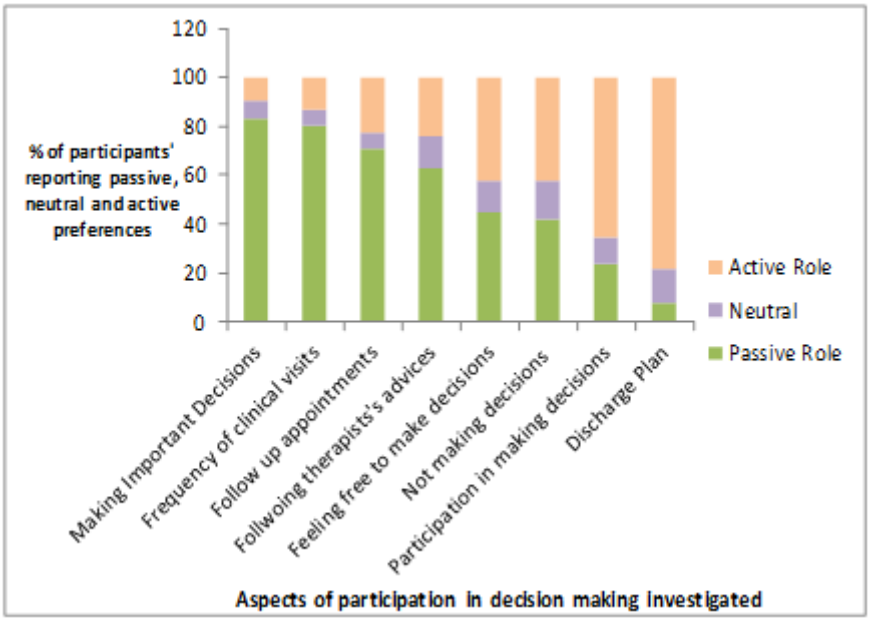

Figure 6.1: Proportions of participants reporting passive, neutral or active roles as general preferences for patient participation in decision making

- **<u>The associations of participants demographic characteristics with their general preferences for patient participation in decision making</u>**

P values of the associations of participants' demographic characteristics with their general preferences for participation in decision making are presented in Table 6.5.

Table 6.5: The association between participants' demographics and their reported general preferences for patient participation in decision making

Participants' reported general views on preferences for patient participation in decision making	Age (years)	Therapist's professional qualification	Therapist's work position	Region
Making important decisions		.036		
Frequency of clinical visits	.019		.001	.035
Going along with therapist's advice		.010		

- Blank cells: Non-significant values at 5% level

The following results report differences in participants' reported preferences; indicating the associations of their demographic characteristics with their preferences for participation in decision making in general (see table 6.3 for the questionnaire items).

1. Making important physiotherapy management decisions:

Unlike physiotherapists with higher degrees, those who had a bachelor degree thought that the important management decisions should be made by the physiotherapist, not the patient (Fisher's exact test: 5.8, df: 1, p=.036) (Table 1: CD Appendix 16).

2. Following physiotherapists' advice:

Physiotherapists' professional qualifications were associated with their preferences for whether patients should go along with the therapist's advice even if they disagreed with it. Most of those with a qualification higher than a bachelor degree did not think that patients should follow advice with which they disagreed (Fisher's exact test: 7,4, df: 1, p=.010) (Table 2: CD Appendix 16).

3. Frequency of visits to physiotherapy department:

Preferences for involving patients in deciding the frequency of clinical visits to the physiotherapy department were associated with age, work position, workload and geographical region. Preferences for patient participation in such decisions were more among younger therapists (Fisher's exact test: 7.9, df:2, p=.019), among those having a more senior position than staff physiotherapists (Fisher's exact test: 11.3, df: 1, p<.001). In addition, all participants working in Jeddah and a strong majority of those in Dammam disagreed with letting patients take part in making decisions about the frequency of clinical visits, whereas less disagreement was observed among those working in Riyadh (Fisher's exact test: 6.1, df: 1, p=.035) (Table 3: CD Appendix 16).

- **Associations and interactions between the explanatory variables identified in Chi-square tests**

The ordinal regression modelling revealed that participants' general preferences for patient participation in decision making were significantly explained by their professional qualification and work position; see Table 6.6.

Table 6.6 : Results of Tests of Model effect and 'Parameter Estimates' of factors' interactions in association with participants' general preferences for patient participation in decision making

The Outcome Variable/s	The explanatory variable/s	Estimate	Std. Error	df	P-value
Making important decisions	Professional qualification	20.208	1.658	1	.001
Frequency of physiotherapy visits	Work position	15.825	1.069	1	.001

Std. Error: Standard Error; **df**: degree of freedom

6.5.3.2 Participants' specific preferences for participation in making decisions about various aspects of the physiotherapeutic process

This subsection presents participants' preferences for patient participation in making decisions about various aspects of the physiotherapeutic process; in addition to factors associated with it. Items concerning these preferences are presented in Table 6.7.

Table 6.7: Questions addressing preferences for patient participation in making decisions about specific aspects to the therapeutic process

Question number	Questions addressing preferences for patient participation in making decisions about specific aspects to the therapeutic process
9	Whether patients should change/adjust their routine daily activities
10	When patients are ready to carry out their routine daily activities
11	What type of treatment patients should receive in the physiotherapy department
12	Whether patients should pursue a home management programme following their visits to the physiotherapy department
13	How frequently patients should be seen by their physiotherapists
14	How much supervision patients need during physiotherapy treatment sessions
15	When a more senior physiotherapist should be consulted about patients' LBP management
16	Whether patients need to be referred back to their treating physician
17	When patients should be discharged from physiotherapy services

Participants' reported preferences for patient participation in making specific decisions involved their views on who should make decisions in particular clinical situations. These are presented in Table 6.8 as proportions in each category before summation and in Figure 6.2 after summation, for simplicity and clarity. These preferences are classified into three categories: decisions to be made predominantly

by the patient, shared equally with the therapist or predominantly by the therapist. A general preference was observed for participants preferring decisions to be either made or controlled by physiotherapists. However, when decisions were related to patient daily activities or home programmes, participants preferred more patient participation. A strong preference was noticed for decisions to be made by therapists rather than patients when these related to the type of treatment that patients should receive to manage their LBP.

Table 6.8: Proportions of participants reporting preferences for clinical decisions to be made: predominantly by patients, sharing equally or predominantly by physiotherapists

Aspects of participation in decision making investigated	Total number of responses (n=93)	The therapist alone	Mostly the therapist	Therapist and patient equally	Mostly the patient	The patient alone
Changing/adjusting patients' routine daily activities	91	2 (2%)	16 (17%)	60 (66%)	7 (8%)	6 (7%)
Readiness to carry out routine daily activities	91	6 (7%)	22 (24%)	50 (55%)	8 (9%)	5 (6%)
Home management programmes	90	21 (23%)	27 (30%)	30 (33%)	7 (8%)	5 (6%)
Type of treatment patients should receive	91	36 (40%)	47 (52%)	8 (9%)	0	0
Frequency of physiotherapy visits	90	34 (38%)	43 (48%)	11 (12%)	2 (2%)	0
Amount of supervision	89	27 (30%)	48 (54%)	10 (11%)	3 (3%	1 (1%)
Consulting more senior physiotherapist	89	31 (35%)	47 (53%)	9 (10%)	0	2 (2%)
Referring back to the treating physician	91	30 (33%)	44 (48%)	14 (15%)	2 (2%)	1 (1%)
Discharge from physiotherapy services	91	37 (41%)	36 (40%)	17 (19%)	1 (1%)	0

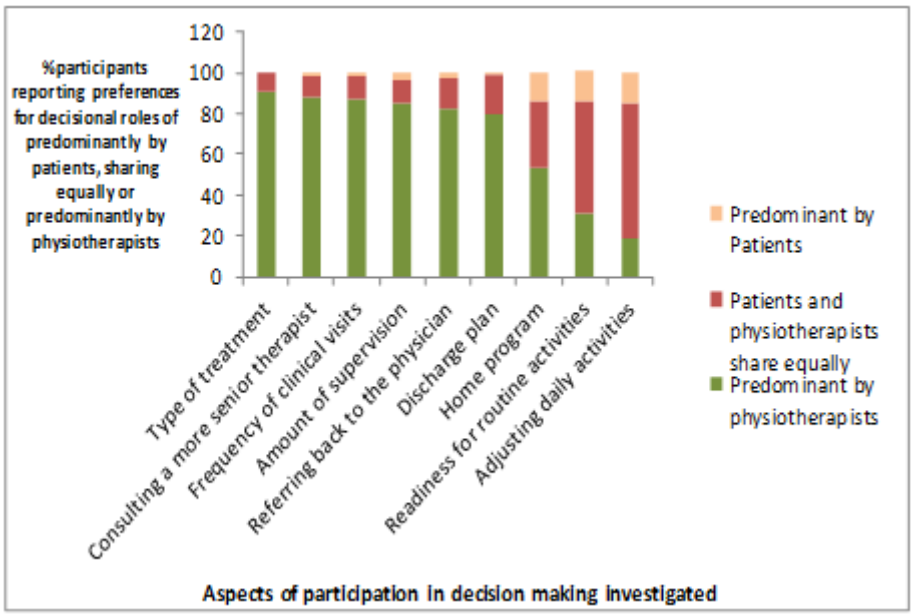

Figure 6.2: Proportions of participants reporting preferences for clinical decisions to be made predominantly by patients, shared equally or predominantly by physiotherapists

- **<u>The associations of participants' demographic characteristics with their preferences for patient participation in making decisions about various aspects of the therapeutic process</u>**

P values of the Chi-square tests for the associations of participants' demographic characteristics with their preferences for participation in making decisions about various aspects of the therapeutic process are presented in Table 6.9.

Table 6.9: Associations between participants' demographics and their preferences for patient participation in making decisions about specific aspects of the therapeutic process

Clinical decisions	Age	Therapist's professional qualifications	Therapist's work position	Hospital type	Therapist's workload	Region
Readiness to carry out routine daily activities					.027	.031
Home management programmes	.019					
Type of treatment		.022				
Consulting more senior physiotherapist	.004		.042	.038		

- Blank Cells: Non-significant values at 5% level

The following present differences in participants' reported preferences indicated the existence of associations between participants' demographics and their preferences for who should make decisions concerning a number of aspects of the management of LBP (see Table 6.7 for questionnaire items).

- **Participants' preferences for who should decide on patient self-management**

This involved making decisions on patient adjusting daily activities and readiness to carry out routine activities.

1. Readiness to carry out routine daily activities:

Participants who saw more than five patients weekly preferred such decisions to be made either jointly or predominantly by patients, while those who saw fewer than five patients weekly preferred them to be made either jointly or predominantly by therapists (chi: 7.2, df: 2, p=.027). In terms of geography, most participants working in Jeddah preferred joint decisions, but none of them preferred patients to take the lead. Participants working in Riyadh differed slightly in that a few preferred such decisions to be made predominantly by patients. However, those working in Dammam seemed not to have a preference regarding these decisions, compared to those from Jeddah and Riyadh (Fisher's exact test: 10.2, df: 4, p=.031) (Table 4: CD Appendix 16).

2. Home management programmes:

Most of the older and the younger groups thought that such decisions should be made mostly by therapists, whereas the middle age group was more likely to prefer a shared role than the other two age groups. Provision patients the predominant role in making this decision was also significantly less popular among the older and younger groups than among the middle group (Fisher's exact test: 11.5, df: 4, p=.019) (Table 5: CD Appendix 16).

- **Patients' preferences for who should decide about decisions concerns clinical situations**

3. Type of Treatment:

In general, none of the participants preferred patients to take a role in deciding about treatment type. However, there was a of participants holding higher degrees to prefer more sharing role (Fisher's exact test: 7.2, df: 2, p=.022) (Table 6: CD Appendix 16).

4. Consulting more senior participants:

A majority of all age groups preferred them to be made mostly by participants and two of the older participants thought that this decision should be made predominantly by patients, compared to none in the other age groups. Joint decision making was mostly preferred by the younger group, whereas none of the older group chose this (Fisher's exact test: 10.8, df: 4, p=.004). Although a strong majority of both groups thought that such decisions should be made mostly by participants, with a relatively greater proportion of those with higher degrees holding this view, none of the staff participants and only two of the other group thought that they should be made by patients alone or mostly by patients. Very few participants in either group preferred a shared role, but more staff therapists did so than others (Fisher's exact test: 5.5, df: 2, p=.042). All participants who worked in university hospitals, in addition to the majority of those from other hospital types, preferred these decisions to be made mostly by therapists, while a shared role was mostly preferred by participants working in military hospitals. None of the participants who worked in university or civilian hospitals preferred such decisions to be made predominantly by patients and only two therapists, one each from a private and a military hospital, chose this category (Fisher's exact test: 10.1, df: 6, p=.038) (Table 7: CD Appendix 16).

- **Associations and interactions between the explanatory variables identified in Chi-square tests**

Based on the results revealed by the univariate analysis (see above in Table 6.9) the outcome and explanatory variables were selected to enter the ordinal regression model.

Results revealed by the ordinal regression modelling revealed that region of Kingdom and participants' professional qualification were found most significantly explain their specific preferences for patient participation in making decisions about specific aspects of the therapeutic process; see Table 6.10.

Table 6.10 : Results of Tests of Model effect and 'Parameter Estimates' of factors' interactions in association with participants' preferences for patient participation in making decisions about specific aspects of the therapeutic process

The Outcome Variable/s	The explanatory variable/s	Estimate	Std. Error	df	p-value
Readiness to carry out routine daily activities	Region of Kingdom	1.188	.473	1	.012
Type of treatment	Professional qualification	17.239	.938	1	.001

Std. Error: Standard Error; **df**: degree of freedom

6.5.3.3 Participants' overarching preference for patient participation in decision making and associated factors

This section addresses the last part of **'Aim 1'** of the current study; identifying and examining patients' overarching preference for participation in decision making. The identified preferences are presented in Table 6.11. More than three-quarters of participants (78%) stated an overall preference for clinical decisions to be either taken or controlled by physiotherapists, while 14% preferred to share this responsibility equally with patients, but none of them preferred to leave the overall decision to the patient alone.

Table 6.11: Participants' overarching preferences for patient participation in decision making

Participants' preferences	Number of responses	Therapist makes the decision alone	Therapist makes the final decision	Patient and therapist make decisions together	Patient makes the final decision	Patient makes the decision alone
	90	24 (27%)	46 (51%)	13 (14%)	7 (8%)	0

- **<u>The associations of participants' demographic characteristics with their overarching preference for patient participation in decision making#</u>**

The univariate analysis revealed no significant associations between participants' demographics and their overarching preference for patient participation in decision making. However, using the ordinal regression modelling revealed that professional qualification significantly explains participants' preferences in this section. This result is shown in Table 6.12.

Table 6.12 : Results of Tests of Model effect and 'Parameter Estimates' of factors' interactions in association with participants' preferences for patient participation in making decisions about specific aspects of the therapeutic process

The Outcome Variable/s	The explanatory variable/s	Estimate	Std. Error	df	p-value
Participants' preference for the overall attitude to participation in decision making	Professional qualification	-22.176	1.783	1	.001

Std. Error: Standard Error; **df**: degree of freedom

6.5.4 Participants' preferences for information provision on specific aspects of the therapeutic process

This section addresses '**Aim 2**' of the current study 'identifying and examining participants' preferences for information provision on specific aspects of the therapeutic processes, and the association of participants' demographic factors with these preferences'. Participants were asked to report their preferences in response to the items listed in Table 6.13.

Table 6.13: Questions addressing preferences for information provision on specific aspects of the therapeutic process

Question number	Questions addressing preferences for information provision on specific aspects of the therapeutic process
19	Patients should be given information only when they ask for it
20	Patients should have a good understanding of their LBP
21	Informing patients is an essential part of any physiotherapy management for LBP
22	If the level of patient' s back pain changes, they should be given more information about what is happening to their back
23	If the news about patient's back pain is bad, they should be fully informed
24	I should explain the purpose of any physiotherapy clinical examinations that I use when assessing of patient's LBP
25	When there is more than one method to treat patient's LBP, they should be informed about each one
26	It is important for patients to know all the possible adverse effects of any physiotherapy interventions used to manage their back pain

Participants' preferences for providing patients with information about managing their LBP are presented in Table 6.14 and Figure 6.3. A general consensus on information provision was observed. Participants' strongest desire was to give information seen as an essential part of the management process, allowing their patients to have a good understanding of their LBP problem and providing them with information when the level of pain changed or when the news was bad.

Table 6.14: Proportions of participants reporting preferences for giving information on specific aspects of the therapeutic process

Aspects of information giving	Total number of responses (n=93)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Giving information only when patients ask for it	91	40 (44%)	36 (49%)	2 (2%)	6 (7%)	7 (8%)
		83% (strong desire)		**Neutral**	**15% (weak desire)**	
Information is essential part of physiotherapy management	90	0	0	1 (1%)	25 (28%)	64 (71%)
		0		**Neutral**	**99% (strong desire)**	
Patient having a good understanding of LBP	91	0	0	1 (1%)	26 (29%)	64 (70%)
		0		**Neutral**	**99% (strong desire)**	
Giving information if pain level changes	91	0	0	2 (2%)	36 (40%)	53 (58%)
		0		**Neutral**	**98% (strong desire)**	
Giving information if the news is bad	89	1 (1%)	2 (2%)	14 (16%)	34 (38%)	38 (43%)
		3% (weak desire)		**Neutral**	**81% (strong desire)**	
Information about the purpose of physiotherapy clinical examinations	91	1 (1%)	9 (10%)	7 (8%)	38 (42%)	36 (40%)
		11% (weak desire)		**Neutral**	**81% (strong desire)**	
Information about methods of physiotherapy to manage LBP	**91**	0	13 (14%)	10 (11%)	42 (46%)	26 (29%)
		14% (weak desire)		**Neutral**	**75% (strong desire)**	
Information about possible adverse effects	91	1 (1%)	4 (4%)	6 (7%)	42 (46%)	38 (42%)
		5% (weak desire)		**Neutral**	**88% (strong desire)**	
Key: Participants' preferences in relation to giving information: **Maroon**: strong desire, **purple**: weak desire, **blue**: neutral.						

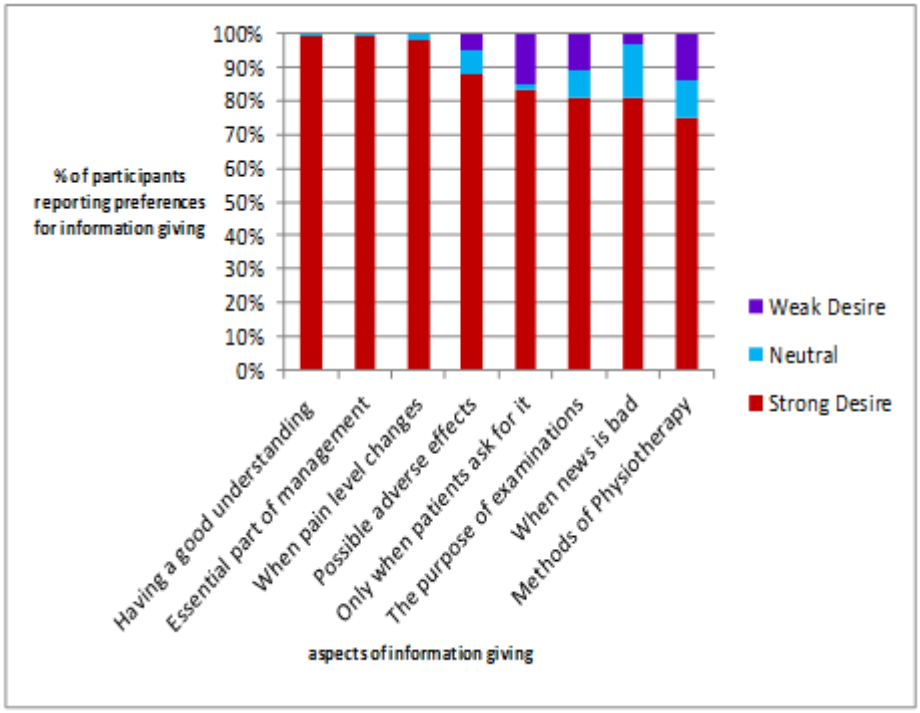

Figure 6.3: Proportions of participants reporting preferences for giving information on specific aspects of the therapeutic process

The associations of participants' demographic characteristics with their preferences for information provision

No significant associations was found between participants' demographics and their preferences for information provision on specific aspects of the therapeutic process

6.5.5 The association between patients' pre-management preferences and their perceived experiences during a recent physiotherapy course

This section addresses '**Aim 3**' of the current study 'examining the association between participants' preferences and their perceived practices during a recent physiotherapy course'. Participants were asked to report their perceived experiences in response to the questions listed in Table 6.15 below.

Table 6.15: Questionnaire items addressing participants' practice of patient participation in decision making and information giving during their most recent physiotherapy course

Question number	Items addressing therapists' experience with patient involvement in decision making and information provision during their most recent course of treatment of LBP patients
27	How much did the patient participate in the decision-making process?
28	How much information did you give to your patient about their LBP?
29	Do you think the severity of patient's pain affected how much she/he wanted to be involved in the decisions made by you?
30	How much did you encourage the patient to participate in making decisions about the management of her/his LBP?
31	How much did you encourage the patient to gather information she/he wanted from you about her/his LBP and its management?
32	Do you think your decisions about patients' LBP affect their adherence to the plan of management?
33	Type/s of information received during physiotherapy treatment course
34	Reported factors that influenced participants' attitude to patient involvement in decision making and information giving

Table 6.16 summarises participants' most recent experiences of patient involvement in making decisions and provision of information on managing their LBP. In general, the data indicate a positive attitude towards engaging and encouraging patients to participate in making clinical decisions and to gather information about their LBP. Only a few participants reported that patients did not gather information or participate in making clinical decisions and that they did not encourage patients to do so. In addition, most participants thought that their attitude to patient involvement in

decision making during physiotherapy had influenced patients' adherence to the treatment course provided.

Table: 6.16: participants' reported practice of patient participation in decision making and information provision during the most recent physiotherapy course

Recent experience of patient involvement in decision making and information provision	No. of responses	Not at all	A little	A fair amount	A lot	A great deal
Patients' participation in decision making	90	13 (14%)	27 (30%)	33 (37%)	15 (17%)	2 (2%)
Patients' information gathering	90	0	3 (3%)	24 (27%)	40 (44%)	23 (26%)
Influence of severity of patients' pain on their involvement in decision making	90	5 (6%)	12 (13%)	29 (32%)	35 (39%)	9 (10%)
Encouraging patients to participate in decision making	89	10 (11%)	19 (21%)	25 (28%)	27 (30%)	8 (9%)
Encouraging patients to gather information	90	2 (2%)	10 (11%)	25 (28%)	38 (42%)	15 (17%)
Influence of participants' attitudes on patient adherence	89	4 (5%)	6 (7%)	17 (19%)	47 (53%)	15 (17%)

- **Participants' reported practice of type/s of information given to patients during their most recent course of non-specific LBP physiotherapy treatment**

Table 6.17 shows the types of information that participant reported having given to patients during their most recent experience of physiotherapy settings. About 10% of the information given concerned explanations of various types of exercise. The types most often given involved: self-management programmes, spine biomechanics and healthy posture, and preventive management strategies.

Table 6.17: Reported types of clinical information given by participants to patients during the most recent clinical case of non-specific LBP

Reported type/s of information given to patients with LBP	Number of responses (n=93)	Percentage %
Back pain in general	44	47
Spine biomechanics and healthy posture	68	73
Pain behaviour & management	59	63
Self-management programmes	76	82
Preventive management strategies	65	70
Common physiotherapy management for LBP	58	62
Others	9	10

- **Factors reported by participants as influencing their attitudes to patient participation in decision making and information provision**

The factors most often affecting participants' attitudes to patient involvement in decision making were the patient's age, level of education and behavioural or psychological wellbeing. Proportions of these responses, in addition to other factors, are presented in table 6.18.

Table 6.18: Factors reported as influencing participants' attitudes to patient involvement in decision making and information giving

Factors reported to influence participants' attitude to patient involvement in decision making and information giving	Number of responses (n=93)	Percentage %
LBP condition	55	59%
Age	60	65%
Level of education	58	62%
Social/cultural background	37	40%
Behavioural/ psychological wellbeing	59	63%
Patient feedback on treatment plan	47	51%

- **<u>The associations of participants' demographic characteristics with their perceived experiences during their current course of physiotherapy treatment</u>**

p-values of the Chi-square tests for the associations of participants' demographic characteristics with their perceived practice during a course of physiotherapy are presented in Table 6.19.

Table 6.19: Association between participants' demographics and their reported experience during the most recent clinical case of non-specific LBP

Participants' recent experience of patient involvement in decision making and information giving	Age (years)	Gender	Work position
Patient participation in decision making	.036		
Patient information gathering		.026	
Encouraging patients to participate in decision making			.018
Influences of participants' attitudes on patient adherence		.005	

- Blank cells: Non-significant values

- **Participants' reported practice of patient involvement in decision making during the most recent clinical case of non-specific LBP**

A few physiotherapists reported that their patients participated 'a lot' or 'a great deal' in the decision-making process; however, a majority in the younger group and almost as many of the older physiotherapists reported that their patients either did not participate at all or that they did so just a little. Therapists in the middle group by age were most likely to report a fair amount of participation by patients (chi: 10.3, df: 4, p=.036). In addition, staff physiotherapists were less likely than the other physiotherapists to report provision a lot of encouragement to their patients to participate; and they were more likely to report that their patients did not participate at all or did so just a little, compared to other physiotherapists (chi: 8.02, df: 2, p=.018).

- **Participants' reported practice of provision information during their most recent course of physiotherapy treatment of patients with non-specific LBP**

Most physiotherapists in each gender group reported that their patients gathered a great amount of information from them about their LBP; however, the rate was higher among male physiotherapists. Female physiotherapists were more likely than male physiotherapists to report provision a fair amount of information (Fisher's exact test: 6.4, df: 2, p=.026). Moreover, a clear majority of physiotherapists thought that their decisions about patient's LBP mostly affected patients' adherence to the plan of management; however, the rate was higher among male therapists, while females were more likely than males to give responses in the 'fair amount' category and less likely to reply 'not at all' or 'a little' (Fisher's exact test: 9.8, df: 2, p=.005).

- **<u>Associations and interactions between the explanatory variables identified in Chi-square tests</u>**

  Based on the results revealed by the univariate analysis (see above in Table 6.19) the outcome and explanatory variables were selected to enter the ordinal regression model. The multivariate analysis revealed that physiotherapists' years since graduation and the average of the new patients seen weekly significantly

explain their perceived practice during a most recent physiotherapy course to manage patients with LBP (see Table 6.20).

Table 6.20: Results of Tests of Model effect and 'Parameter Estimates' of factors' interactions in association with participants' perceived during a most recent physiotherapy course to manage patients with LBP

The Outcome Variable/s	The explanatory variable/s	Estimate	Std. Error	df	p-value
Patient participation in decision making	Years since graduation	-1.565	.673	1	.020
Patient information gathering	Average of new patients	-.995	.504	1	.049

Std. Error: Standard Error; **df**: degree of freedom

6.6 Discussion

The present study explored the preferences of physiotherapists treating patients with LBP for patient participation in decision making and information provision. Factors associated with physiotherapists' preferences were identified. This section summarises and discusses the main findings, relates the results to the relevant literature, presents methodological critique, and highlights the implications of this study for practice.

6.6.1 Summary and discussion of main findings

The overall findings of the present study show that many physiotherapists had a strong preference to make clinical decisions on behalf of patients regarding the management of their LBP; suggesting a preference to adopt a relatively paternalistic approach, an approach in which clinicians prefer to dominate the decision making process and make decisions alone about patients' needs, (Charles et al., 1997, Gafni et al., 1998, Charles et al., 2003).

Results derived from exploring the physiotherapists' general views of patient involvement in decision making show that a strong majority (83%) thought that patients should not make important decisions about their physiotherapy care and that they should follow their physiotherapists' advice, even if they disagreed with it (63%). Thus, they thought that patients should participate to some extent in decision

making, but within a number of boundaries: 1) patients should not make important decisions; 2) they should not feel free to make treatment decisions; and 3) they should go along with physiotherapists' advice even if they disagreed with it. These boundaries indicate that some situations may exist under which physiotherapists may accept patient participation in clinical decision making; however, the results do not specify in what ways physiotherapists might prefer patients with non-specific LBP to participate. These areas were thus identified as needing to be investigated in depth in the qualitative phase of the current study. These views do not indicate an extreme paternalistic style among many clinicians, though some at one end of the spectrum did hold such views. By comparison, the results derived from asking physiotherapists' about their preferences as to who should make the decisions in various specific clinical aspects were more consistent, with a paternalistic style being the dominant approach. Thus, their responses indicate a strong preference for clinical decisions to be either made or controlled by themselves, rather than having patients involved in making such decisions. Support for this preference ranged from 81% to 92% in response to questionnaire items concerning decisions related to specific clinical situations. Moreover, none of the participants thought that decisions about type of treatment should be either made or controlled by patients, although a small proportion (9%) expressed a preference for these to be made jointly with the patient.

This apparent inconsistency between preferences generated in response to more general statements compared to those related to specific aspects of care may arise for a number of reasons. It may be that the hypothetical nature of these 'general views', with a lack of clarity about detail allows them to be more open in their views. Once the specific elements were introduced it seems that the physiotherapists were much more cautious. The inconsistency in reported views may also be related to the overlapping of various levels of decisions to be made during clinical encounters, as suggested by Charles and colleagues (1997) in their characterization of a model of SDM.

This study showed that a large majority of physiotherapists regarded information as an essential part of the management process. They also thought that patients should have a good understanding of their LBP problem and should be provided with

information when the level of pain changed or when the news about patients' back pain was bad. Although a strong desire to give information was observed among the physiotherapists who took part in this study, it is unclear whether they perceived this type of information giving as a way to involve patients in decision making. Their strong desire to give clinical information may indicate physiotherapists' willingness to educate patients about their LBP condition and its physiotherapy management, but not necessarily to involve them in making treatment decisions.

In general, these participants demonstrated a strongly paternalistic approach, with limited willingness to involve patient in their health care. The level of paternalism suggested by these preferences expressed by these practitioners can potentially lead to a number of problems. The approach can reduce patients' self-reliance (Makoul, 1998, Nys et al., 2007) and their perceived self-control may also be a barrier to implementing SDM in clinical settings (Müller-Engelmann et al., 2011). It can be compounded by patients' 'assumptions' that better decisions are made by clinicians (Sekimoto et al., 2004). The current finding that a preference for clinical decisions to be made by physiotherapists dominates practice in the management of patients with LBP in Saudi Arabia is not unexpected, and one key reason may be that the biomedical model is regarded as default clinical practice in Saudi Arabia (see chapter one). Paternalism among physiotherapists may also be attributed to their perception that they are the experts, their desire to implement evidence based practice and concerns about a loss a professional credibility in the eyes of the patient. Given this, it remains interesting to note some evidence that some practitioners were willing to share some aspects of decision making with their patients. This might be accounted for by those therapists who were not locally trained, had worked in a models of care that were more psychosocially orientated or – as noted with patient preferences – worked in the military hospitals. Further discussion of paternalism is provided in chapter eight.

6.6.2 Discussion of main findings in relation to the literature review

The overall preference for making the overarching final decision indicated that more than three-quarters (78%) of physiotherapists who took part in the current study

believed that decisions should be made predominantly by the therapist, while only 14% of participants stated a preference for sharing this responsibility with patients. Comparing this finding to those in other medical disciplines, it is surprising that physiotherapists showed a greater tendency to prefer a paternalistic style than did physicians and surgeons. For example, the current findings concerning overarching preferred decisional styles are in contrast with those reported by McKeown and colleagues (2002) in a study of residents' general perceptions of patient participation in decision making; however, as recently graduated practitioners, all of the participating residents were under 30 years old. Our findings are also inconsistent with results obtained by Murray and colleagues (2007) in a cross-sectional survey of 1040 American physicians with various medical specialities. They found that relatively few physicians preferred the paternalistic style of decision making, while 75% preferred SDM. Charles and associates (2004) also found that SDM was preferred by up to 89% of surgeons and oncologists (n=450); however, their data may have been influenced by information about the importance of SDM that physicians had been given before their preferences were assessed. These studies are all based in western settings where the biopsychosocial model of care is dominant and where increasingly patient participation in care and 'patient centred care' is advocated. In addition, policy papers are increasingly advocating shared decision making as a key policy.

While most responses indicated that therapists thought that patient should not participate in most identified and specific aspects of care, when decisions concerned patients' daily activities, a majority of physiotherapists (ranging from 55% to 66%) preferred SDM. While, still willing to involve patients, they sought a stronger role in making decisions regarding home management programmes (55%), perhaps because they considered these to be part of their clinical responsibility for patient education, based on their clinical expertise. They may have wished to implement evidence based practice such as the finding of Moseley and colleagues (2002) that a combined physiotherapy and education approach was found beneficial to patients with chronic LBP. Evidence on managing LBP also suggests that home programmes are often prescribed by therapists and that patients are expected or required to comply with

these plans, as decisions on their volume and intensity constitute part of the LBP management plan (Descarreaux et al., 2002, Broonen et al., 2011, Dean et al., 2005).

When we examined the results in relation to the demographic characteristics of the sample, results varied. In some instances no relationship was found. For example, a high consensus was observed in that most participants reported that the overarching decision on physiotherapy care should be made by physiotherapist; this was not associated with any demographic variable and indicates a broad preference for a limited input of patient participation. When examining the remaining decision making scenarios, it was found that preferences as to whether patients should decide on frequency of clinical visits were the most strongly influenced by demographics, in addition to preferences concerning patient participation in making decisions on readiness to carry out routine daily activities and consulting a more senior physiotherapist. In general, a negative association was found between demographic characteristics and preferences for patient participation when physiotherapists were younger, inexperienced, working in Jeddah and overloaded with numbers of patients seen per week. Overall, the current findings may be affected to a number of factors, such as the physiotherapists' desire to control the clinical environment, time constraints during treatment sessions and the high volume of clinical work. These potential reasons however need investigation. Research to date provides varied results in other contexts. In agreement with the current findings, Kaplan and colleagues (1996) correlated physicians' characteristics with clinical decision making as reported by patients and found that physicians' age, clinical experience and training, personal behaviour, medical speciality and workload had significant influences on physicians' attitudes to patient involvement in decision making. The authors report a negative association between workload and implementing a participatory style of decision making, for example. In a rather more limited study findings Ruiz-Moral and colleagues (2006) indicate that physicians communicate better when their patients are young and well educated, while physicians' age, gender and patients' previous experiences with their doctors did not influence patients' perceptions of physicians' communicative behaviour during medical encounters. In effect, a positive and good clinical communication between patients

and professionals can result in facilitating SDM process (Young et al., 2008). Young and colleagues (2008) used the OPTION scale to assess physicians' behaviour in respect of patient involvement and found that older physicians showed a limited tendency to adopt SDM when treating patients with depression, this emphasising the role of age in affecting behaviour and by extension preferences. Age may be important in that the role of practitioners and models of health care have changes considerable in the past 2-30 years and not all practitioners will have changes in parallel; however, no studies have been found addressing this.

Level of experience may also be a factor. None of the physiotherapists responding to the current questionnaire preferred decisions about type of treatment to be made by patients alone or predominantly by patients. However, a tendency towards sharing this responsibility was observed when the physiotherapists had higher qualifications and work positions; lower professional qualifications were positively associated with adopting a more paternalistic pattern. Although the level of qualification does not necessarily indicate the extent of clinical experience, it is possible that the extent of knowledge and awareness of SDM was greater in the more highly qualified group. Both qualifications and work position are likely to be correlated to some extent with experience. More experienced clinicians are more likely to process their decision making in ways which reflect the accumulation of their clinical experience; thus, having more experience of managing a particular health condition (such as LBP) can add to the familiarity of physiotherapists in their clinical associations with patients (Clarke et al., 2004). Increased clinical experience may widen clinicians' understanding of the value of acknowledging patients' concerns and needs when choosing the type of treatment. This approach towards making physiotherapy decisions may assist a move away from the traditional biomedical model of decision making towards a more collaborative one. Conversely, novice clinicians may focus their attention on clinical reasoning and finding the best reported evidence as ways to make justified decisions, rather than risk shared decisions.

This is supported by a number of studies with physiotherapists examining the similarities and differences between novice and expert practitioners. An early qualitative study by Jensen and colleagues (1992) of differences between experienced

and novice physiotherapists identified a number of attributes, including 1) level of knowledge, which included physiotherapists' understanding of patient responses in coping with their medical condition; 2) physiotherapists' actual performance in controlling the clinical environment, their ability to communicate with patients and their provision of clinical advice and education; 3) the ability to integrate patients' perceptions of their illness with the clinical data, its evaluation and the appropriate treatment. Nineteen years later, Wainwright and colleagues (2011) used the grounded theory method to identify differences between novice and experienced physiotherapists regarding the making of clinical decisions. Their main finding was that experienced therapists often used clinical interactions with their patients to guide clinical decision making and used various information sources to inform their professional practice, while novice therapists tended to rely on their anticipation of patient performance, on their previous personal experience and on the available evidence to guide their clinical decision making. However, a common feature between novice and experienced therapists was their observation of patients' motivation to participate in making clinical decisions as a major determining factor.

- Information provision

In the present study, the general consensus among physiotherapists on preferences for information provision was in contrast to the above results, with a smaller percentage of physiotherapists (11-15%) reporting that information should be given only when patients asked for it. While evidence from other medical disciplines suggest that clinicians' provision of clinical information is a prerequisite step to enable or empower patients to be part of the SDM process (Charles et al., 1997, Elwyn et al., 2011), a number of participants in this study showed a weaker desire to give information explaining the purpose of clinical examinations and methods of physiotherapy to manage LBP. The reasons for this are not reported but may include time constraints due to the heavy workload and a belief among physiotherapists that their role is that of 'treating clinician' rather than 'health educator'. Practitioners may encounter different view about their role in the literature. Whitney and colleagues (2008) suggest that clinicians are responsible for providing clinical information to their patients only if they are unaware and that patients should not

rely on their clinicians as their only source of information. However a recent non-systematic review of 52 articles on patient education and managing LBP (Dupeyron et al., 2011) recommended that the bio-psychosocial model should inform approaches to 'therapeutic patient education', considering patient needs, level of knowledge and level of satisfaction. No studies examining preferences have however been identified.

- Perceived clinical practice

While the current study explored the stated preferences of physiotherapists and their perceived roles during their clinical experience, it did not aim to observe their actual behaviour towards patient involvement in decision making. However when the results arising from physiotherapists' stated preferences and their reported actions during practice some discrepancy is seen. Although their overall preferences for patient participation indicated a relatively passive role for themselves, this was not reflected by participants' reports of their most recent experience with patients, with as many as 39% of physiotherapists stating they encouraged patients to participate in making treatment decisions during physiotherapy encounters. Similar numbers (44%) however reported low levels of patient participation in practice. In contrasts with the work of Murray and colleagues (2007) who report a high consensus between preferred and perceived decisional styles when treating patients with a wide range of medical conditions. They also found that physicians who preferred SDM encouraged their patients to gather information more than others. This suggests a reciprocal interaction between the two domains of SDM: information provision and decision making; patients' abilities to understand clinical information facilitates active participation and vice versa.

There were no major significant associations between physiotherapists' demographic characteristics and their reported recent clinical behaviour with respect to patient involvement in decision making and information provision. Results of the study by Murray and colleagues (2007) indicate that younger physicians reported a closer match between their preferred and perceived styles of decision making in relation to patients involvement, while female physiotherapists reported more information gathered by their patients from them during physiotherapy sessions. Although no

significant gender differences were observed in our study regarding encouraging patients to gather information, the increased proportion in amount of information that was reported to be gathered by patients as reported by female physiotherapists can be attributed to the information-seeking behaviour of female patients rather than the information-giving preferences of the treating therapists. However, women physicians have been reported as exhibiting more facilitating behaviours towards patient involvement than men (Zandbelt et al., 2006). This is consistent with other evidence suggesting that physicians' gender was a determinant factor associated with behaviour facilitating patient involvement: female physicians displayed behaviour more conducive to patients' active participation in decision making (Roter et al., 2002). It may be that our findings are related to the fact that physiotherapists in Saudi Arabia usually treat patients of the same gender but this required further investigation.

The hospitals involved in this study have no fixed policy regarding the provision of clinical information to patients with LBP. Hence, the quantity, quality and ways of delivering information will be determined by physiotherapists. This may be affected by their experience, the time available, patients' preferences and readiness to receive information and the level and quality of clinical communication and interaction between physiotherapists and patients (Dupeyron et al., 2011, Müller-Engelmann et al., 2011). Interestingly, the information most often reported to be given in this study was about self-management programmes and preventive strategies; this suggests that physiotherapists were aware of the value of patients having some control over the management of their LBP, so they had no restrictions in teaching patients the correct approaches to avoid pain independently and to self-manage their condition when away from the clinical setting.

The actual experience of patient involvement in decision making may be guided by factors other than individual preferences, such as timeframe and other situational circumstances related to the clinical environment, including patient characteristics (Müller-Engelmann et al., 2011, Thompson et al., 1993). Physiotherapists who took part in the current study reported that patient age, psychological wellbeing, level of education and severity of LBP were major factors determining their engagement of

patients in making clinical decisions during their most recent experience of managing patients with LBP. Murray and colleagues (2007) report that physicians' paternalism was associated with patients' medical condition and more dominant with older patients; possibly reflecting the therapists' views. Further work reinforces the view that severity of the condition can affect behaviour – and suggests that preferences are modified accordingly with, for example, severity of depression affecting approaches (Young et al., 2008). Cardiologists are similarly reported as least likely to involve patients with these serious conditions in making treatment decisions (Kaplan et al., 1996). Zandbelt and colleagues (2006) reported that SDM was inhibited by severity of the medical condition, but that physicians' behaviour was often influenced by situational circumstances; thus, physicians' behaviour tended to vary. The above factors can be reasons that explain physiotherapists' preferences to adopt more paternalistic style of decision making; these factors were discussed further in chapter eleven.

6.6.3 Methodological critique

Advantages of employing a cross-sectional, survey method to collect data about preferences for patient participation and information provision are discussed in chapter three and five. The same key benefits and limitations apply to this study. When conducting this study we encountered a number of specific issues, the key one being the absence national statistics on the number of physiotherapists working in Saudi Arabia. In addition there was no information that might indicate the number treating patients with LBP or the origin of the physiotherapists. This challenged our initial calculation of the number of participants to form an appropriate sample size for this study. Following an initial review of the 'typical' number of therapists in a sample of settings, the number of eligible settings and the requirement of the Research Ethics Committee to access patient and therapist participants from different locations, we decided to devoting the largest number of the involved hospitals to recruit physiotherapists as their numbers in each setting were much lower than those for patients. This resulted in lower numbers being accessed than were indicated theoretically, but was countered by our accessing the total sample of therapists

available to us. We also noted that, while the aim of the study was to examine practice in Saudi Arabia, it was not possible to differentiate Saudi physiotherapists from others' nationalities; it is likely therefore that the prior training they had received and experience varied greatly especially as there is a large 'ex pat' community working in the health sector in the country. While, this indicates the possibility of the influence of international experience affecting preferences of patient involvement in decision, it does reflect practice as is currently in place across the participation institutions.

6.6.4 Implications of this study for practice

Shared decision making is of key importance to practicing physiotherapists since managing patient with non-specific LBP chronic LBP contributes heavily to their workload. This type of research may facilitate the transfer of physiotherapy practice from the biomedical model of health care to a more collaborative model of decision making. Physiotherapists' preferences for information provision can empower patients and encourage them to participate actively in decision making process. However, the decreased preferences for sharing decisions' responsibilities with patients can be attributed to therapists' reduced awareness of this type of clinical interaction; therefore this study highlight the importance of reviewing clinical guidelines, in Saudi Arabia, to match with patients' engagement in taking part to decide on their own health care. Further implications to clinical practice are provided in chapter seven.

6.6.5 Conclusion

This study presented physiotherapists' preferences for patient participation in decision making and information provision when managing non-specific LBP. There appears to be discrepancy between physiotherapists' preferences for patient participation decision making and their preferences for information provision. It is unclear; however, whether these preferences are because of the nature of LBP or whether other factors or reasons contribute to physiotherapists' paternalistic style of decision making. Qualitative methods are needed to provide in-depth explanation of physiotherapists' preferences.

Chapter Seven

Study 3: Similarities and Differences between Patients' and Physiotherapists' Preferences for Patient involvement in decision making and information in the Management of Non-specific Low Back Pain

7.1 Introduction

The previous two chapters (five and six) presented two separate studies examining patients' and physiotherapists' preferences for patient involvement in decision making and the provision (gathering and giving) of information during the physiotherapy management of non-specific low back pain (LBP). This chapter presents a secondary analysis to investigate the similarities and differences between patients' and physiotherapists' preferences.

7.2 Aim

This study aims to answer the first research question 'examining similarities and differences in preferences of physiotherapists and patients with non-specific LBP for patient involvement, in decision making and information provision when managing non-specific LBP within physiotherapy context, in Saudi Arabia'.

Objectives: to

1. compare and contrast physiotherapists' and patients' preferences (general, specific and preferences for their overall attitude) for patient participation in decision making, and examine the degree to which demographic factors are associated with these preferences.

2. compare and contrast physiotherapists' and patients' preferences for information provision, and examine the degree to which demographic factors are associated with these preferences.

3. compare and contrast physiotherapists' and patients' perceived experiences/practice of patient participation in decision making and information provision during a most recent physiotherapy course, and examine the degree to which demographic factors are associated with these preferences.

7.3 Data Analysis

Ordinal logistic regression was carried out to examine similarities and differences between groups regarding their preferences. Cross-tabulation was used to present the findings in proportions. Further details of analytical procedures used and the significance level adopted are presented in chapter three and five.

7.4 Results

7.4.1 Similarities and differences in participants' preferences for patient participation in decision making

The following three subsections address '**objective 1**' of the current study (section 7.2).

7.4.1.1 Similarities and differences in participants' general preferences for patient participation in decision making and factors associated with it

Items addressing participants' general preferences for patient participation in decision making are presented in Table 7.1.

Table 7.1: Items addressing general preferences for participation in decision making

The important management decisions should be made by the physiotherapist, not patients.
Patients should decide how frequently they should be seen by their physiotherapists.
Patients in physiotherapy departments should not make decisions about their own care.
Patients should decide whether they need a follow-up physiotherapy appointment.
Patients should go along with the physiotherapist's advice even if they disagree with it.
Patients should feel free to make decisions about their physiotherapy management.
Patients' views should be taken into account in the discharge plan.
Patients should normally participate with physiotherapists in making decisions about their LBP management.

Similarities and differences between participants' groups regarding their general preferences for patient participation in decision making are presented in percentages in Figures 7.1 and 7.2; these indicate the reported general preferences for patient role in decision making (passive or active).

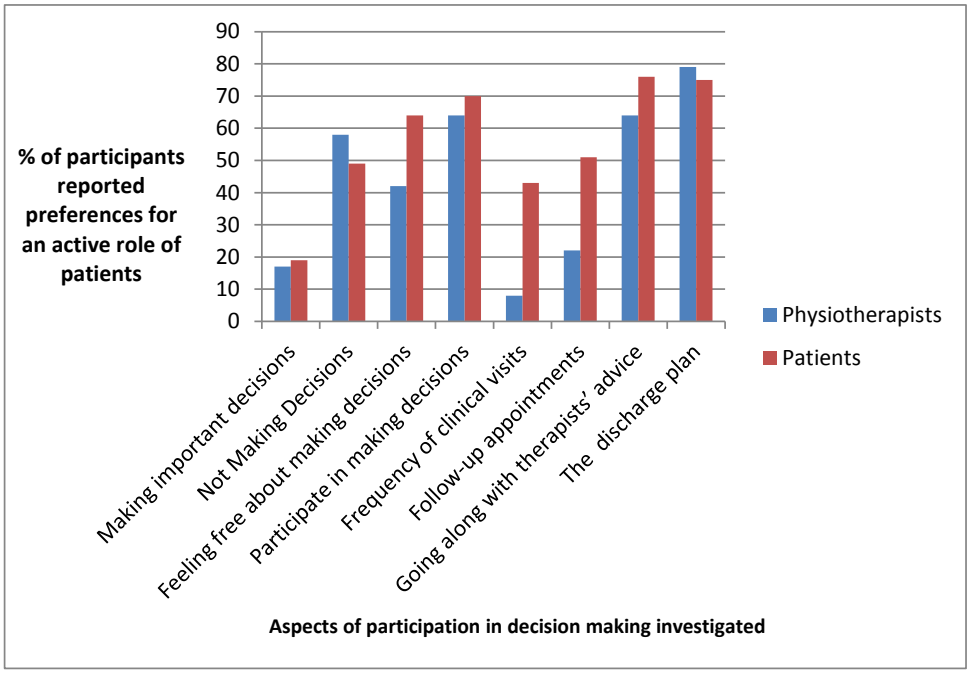

Figure 7.1: Proportions of participants reporting a general preference for patients to adopt an active role in participation in decision making

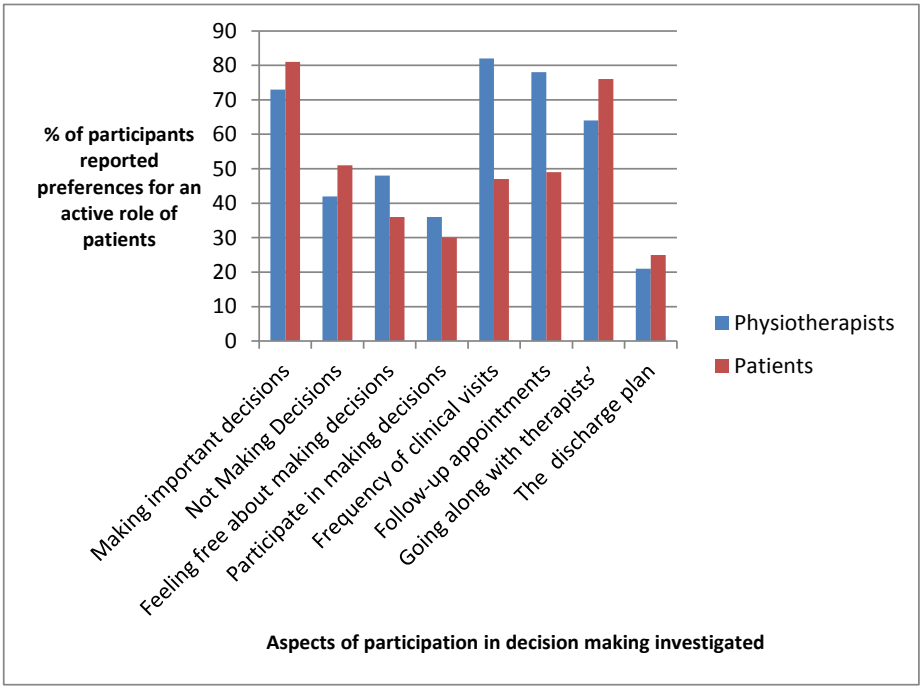

Figure 7.2: Proportions of participants reporting a general preference for patients to adopt a passive role in participation in decision making

Table 7.2 shows percentage of participants reporting general preferences for participation in decision making , in addition to the p-values obtained from the of the 'Parameter Estimates' between groups; using ordinal regression analysis. Only hospital type significantly explain between groups differences in two outcome variables 'The patient should not make clinical decisions' and 'The patient should normally participates in making decisions' ; these effects are shown in Table 7.3.

These results show that physiotherapists preferred patients to adopt more passive roles than patients wanted in the following situations: patients' feeling free to make decisions, frequency of clinical visits and follow-up appointments. Physiotherapists and patients reported similar preferences for **an active role** in situations where patients normally participated in making decisions and in the discharge plan and for **a passive role** when important clinical decisions were being made. The two groups also agreed that patients should go along with physiotherapists' advice even when they disagreed with it.

Table 7.2: p-values identified with ordinal regression analysis to examine differences between groups of participants regarding their general preferences for patient participation in decision making

General preferences for decision making	The patient makes important clinical decisions		The patient should not make clinical decisions		The patient feels free to make clinical decisions		The patient normally participates in making decisions		The patient decides on frequency of clinical visits		The patient decides on follow-up appointments		The patient goes along with the therapist's advice		The patient decides on the discharge plan	
	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH
Total number of respondents	290	91	292	92	291	91	294	92	289	92	289	90	290	91	291	90
Disagree	56 19%	15 17%	143 49%	53 58%	105 36%	53 48%	87 30%	33 36%	164 47%	80 82%	143 49%	70 78%	71 24%	33 36%	73 25%	19 21%
	Active Role		Active Role		Passive Role		Passive Role		Passive Role		Passive Role		Active Role		Passive Role	
Agree	240 81%	77 73%	149 51%	39 42%	186 64%	38 42%	207 70%	59 64%	125 43%	12 8%	146 51%	20 22%	219 76%	58 64%	218 75%	71 79%
	Passive Role		Passive Role		Active Role		Active Role		Active Role		Active Role		Passive Role		Active Role	
p-values (significant at 5% level)	.601		.036		.001		.249		.001		.001		.042		.504	

PT: patients; **PH**: physiotherapists. Participants' preferences in relation to decision making: **orange**: active; **green**: passive

Table 7.3 : Results of Tests of Model effect and 'Parameter Estimates' of factors' interactions in relation to participants' general preferences for patient participation in decision making

The Outcome Variable/s	The explanatory variable/s	Estimate	Std. Error	df	p-value
The patient should not make clinical decisions	Hospital type	.200	.092	1	.029
The patient should normally participates in making decisions	Hospital type	-1.96	.099	1	.048

Std. Error: Standard Error; **df**: degree of freedom

7.4.1.2 Similarities and differences in participants' specific preferences for participation in making decisions about aspects of the therapeutic process, and factors associated with it

Items addressing participants' general preferences for patient participation in decision making are presented in Table 7.4.

Table 7.4: Items addressing preference for patient participation in making decisions related to specific aspects of the therapeutic process

Whether patients should change/adjust their routine daily activities.
When patients are ready to carry out their routine daily activities.
What type of treatment patients should receive in the physiotherapy department.
Whether patients should pursue a home management programme following their visit to the physiotherapy department.
How frequently patients should be seen by their physiotherapists.
How much supervision patients need during physiotherapy treatment sessions.
When a more senior physiotherapists should be consulted about their LBP management.
Whether patients need to be referred back to their treating physician.
When patients should be discharged from physiotherapy services

Similarities and differences between participants' groups regarding their specific preferences for patient participation in decision making are presented as in percentages in Figures 7.3, 7.4 and 7.5.

Table 7.5 shows the proportions on participants' specific preferences in addition to the p-values obtained from the 'Parameter Estimates' between groups; using ordinal regression analysis. None of the independent variables was found significant to explain between groups' differences in their specific preferences for patient participant in decision making.

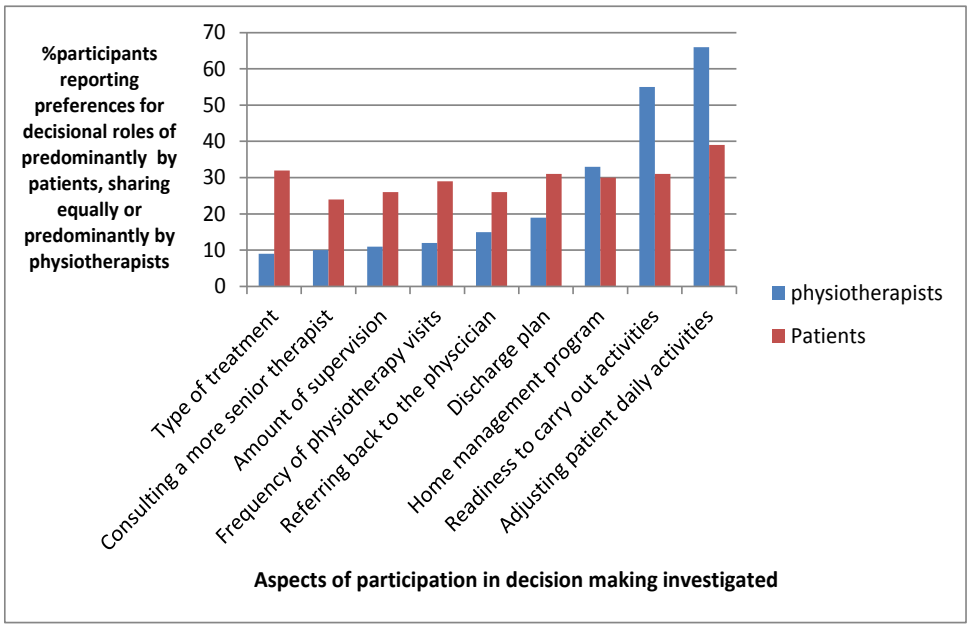

Figure 7.3: Proportions of participants reporting preferences for decisions to be shared equally or made predominantly by physiotherapists

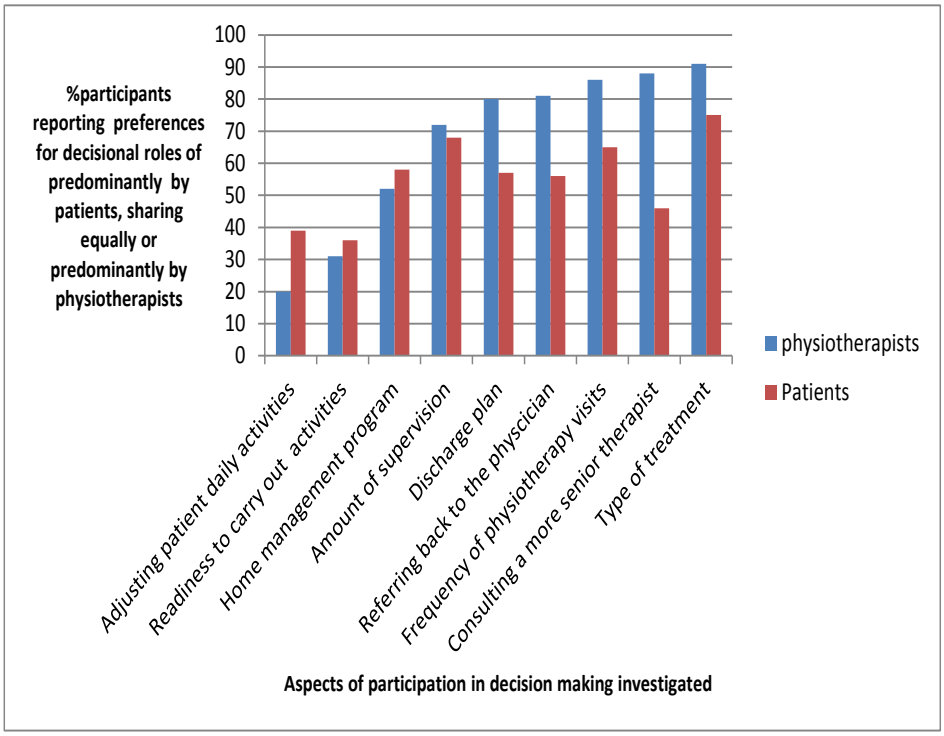

Figure 7.4: Proportions of participants reporting preferences for decisions to be made predominantly by physiotherapists

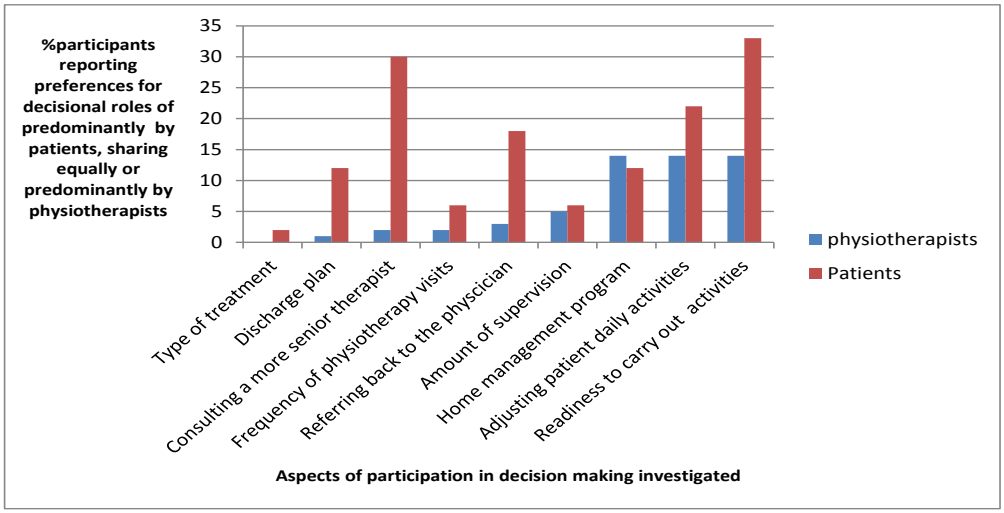

Figure 7.5: Proportions of participants reporting preferences for decisions to be made predominantly by patients

Table 7.5 shows p-values obtained from ordinal analysis for between group differences regarding their preferences for patient participation in making specific decisions about aspects of the therapeutic process. These preferences are presented in percentages. While there was considerable variability in the level of agreement among preferences, with significant differences between the two groups for some items, there was a general preference for decisions to be made by physiotherapists. Physiotherapists showed a preference for **sharing decisions** with patients when decisions were to be made about adjustments to daily activities, about patients' readiness to carry out routine daily activities and about whether patients should pursue a home management programme following their visit to the physiotherapy department. Patients, by contrast, wanted more control by physiotherapists regarding the making of such decisions, although some patients wanted to share with physiotherapists in making them. Physiotherapists preferred patients to adopt **a passive role** when decisions were to be made about the following: the type of treatment that patients should receive; the amount of supervision that patients need; the frequency of physiotherapy visits; when to consult a more senior physiotherapist; when referring back to the treating physician; and the nature of the discharge plan. Although patients preferred more control by physiotherapists in making these decisions, some still preferred to share the task with the therapist. Notably, some patients preferred greater autonomy in making decisions about consulting a more senior physiotherapist, compared to other clinical situations.

Table 7.5: p-values identified with ordinal regression analysis to examine differences between groups of participants regarding their specific preferences for patient participation in decision making

Preferences for who should make the decisions	changing/ adjusting patients' routine daily activities		Readiness to carry out routine daily activities		Home management programmes		Type of treatment patients should receive		Amount of Supervision		Frequency of Physiotherapy visits		Consulting a more senior physiotherapist		Referring back to the treating physician		Discharge plan	
	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH
Total number of respondents	288	91	285	91	281	90	291	91	288	89	283	90	282	89	285	91	287	91
Predominantly by the patient	64 22%	13 14%	94 33%	13 14%	35 12%	13 14%	7 2%	0	17 6%	4 5%	17 6%	2 2%	84 30%	2 2%	51 18%	3 3%	34 12%	1 1%
The physiotherapist & the respondent equally	112 39%	60 66%	88 31%	50 55%	83 30%	30 33%	67 23%	8 9%	76 26%	10 11%	83 29%	11 12%	67 24%	9 10%	74 26%	14 15%	90 31%	17 19%
Predominantly by the physiotherapist	112 39%	18 20%	103 36%	28 31%	163 58%	47 52%	217 73%	83 91%	195 68%	75 72%	183 65%	77 86%	131 46%	78 88%	160 56%	74 81%	163 57%	73 80%
p-values (significant at 5% level)	.001		.001		.859		.016		.029		.019		.123		.787		.510	

PT: patients; PH: physiotherapists. Participants' preferences in relation to decision making: orange: active, green: passive, maroon : shared

7.4.1.3 Similarities and differences in participants' overarching preference for patient participation in decision making and associated factors

Table 7.6 shows the percentage of respondents reporting their overarching preference for patient participation in decision making. Over three-quarters of physiotherapists demonstrated a preference for decisions to be made predominantly by physiotherapists, as did just above half of patients. However, patients demonstrated a much stronger preference than physiotherapists for decisions to be shared (p=.014). None of the independent variables significantly explain between groups' differences in their specific preferences for patient participant in decision making.

Table 7.6: Participants' overarching preference for participation in decision making

Participants' reported overarching preference for patient participation in decision making	Predominantly by the physiotherapist	Patients and therapists share equally	Predominantly by the patient
Patients	148 (51%)	98 (34%)	43 (15%)
Physiotherapists	70 (78%)	13 (14%)	7 (8%)

7.4.2 Participants' preferences for information provision on specific aspects of the therapeutic process

This section addresses '**Objective 2**' of the current study 'examining similarities and differences in participants' preferences for information provision on specific aspects of the therapeutic processes, and the relationship of the demographics to these preferences'. Participants were asked to report their preferences in response to the items listed in Table 7.7.

Table 7.7: Items addressing preferences for gathering/receiving information on specific aspects of the therapeutic process

Patients should be given information only when they ask for it.
Informing patients is an essential part of any physiotherapy management of LBP.
Patients should have a good understanding of their LBP.
If the level of patients' back pain changes, they should be given more information about what is happening to their back
If the news about patients' back pain is bad, they should be fully informed.
Physiotherapists should explain the purpose of any physiotherapy clinical examinations that they use when assessing a patient's LBP.
When there is more than one method of treating a patient's LBP, they should be informed about each one.
It is important for patients to know all the possible adverse effects of any physiotherapy interventions used to manage back pain.

Table 7.5 shows p-values obtained in the 'Parameter Estimates' between groups' using ordinal regression analysis on participants' preferences for information provision. These preferences are presented in percentages.

Significant differences in preferences were observed for the following items: giving information only if patients ask for it; considering information as an essential part of any physiotherapy management; patients having a good understanding of LBP; patients receiving information if the news about their LBP is bad, giving or receiving of information in situations where the pain level changes and when there is more than one method to treat the LBP. No statistically significant differences were observed for information provision about the purpose of clinical examinations or about possible adverse effects of treatment. Despite of these statistical differences, patients and physiotherapists appeared in a general agreement about information gathering and giving. Thus, differences among the observed percentages do not indicate disagreement between the two groups; rather, physiotherapists' desire to give information was found to be stronger than that of patients to gathering it. In addition, none of the independent variables was found significant to explain between groups' differences in their preferences for information provision.

Table 7.8: p-values identified with ordinal regression analysis to examine differences between groups of participants regarding their preferences for information provision

Participants' reported preferences for information provision	Only when patients ask for information		Information is Essential part of any physiotherapy management		Having a good understanding of LBP		If pain level changes		If the news is bad		The purpose examinations		Methods of physiotherapy to manage LBP		Possible adverse effects	
	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH
Total number of respondents	278	91	291	90	291	91	289	91	289	89	290	91	291	91	291	91
Disagree	169 59%	78 86%	39 13%	1 1%	29 10%	1 1%	27 9%	2 2%	31 11%	17 19%	67 23%	17 9%	49 17%	23 25%	45 15%	11 12%
	Strong Desire		Weak Desire		Weak Desire		Weak Desire		Weak Desire		Weak Desire		Weak Desire		Weak Desire	
Agree	118 41%	13 14%	252 87%	89 99%	262 90%	90 99%	262 91%	89 98%	258 89%	72 81%	223 77%	74 81%	242 83%	68 75%	246 85%	80 88%
	Weak Desire		Strong Desire		Strong Desire		Strong Desire		Strong Desire		Strong Desire		Strong Desire		Strong Desire	
p-values (significant at 5% level)	.001		.009		.029		.050		.061		.425		.047		.499	

PT: Patients; PH: Physiotherapists; Blank cells: non-significant values; Participants preferences in relation to information provision: maroon: strong desire, purple: weak desire

7.4.3 Similarities and differences in participants' perceived experiences/practice of patient participation in decision making and information provision during a most recent physiotherapy course, and factors associated with it

This section addresses '**Objective 3**' of the current study 'examining similarities and differences in participants' perceived experiences/practice of patient participation in decision making and information provision during a most recent physiotherapy course, and factors associated with it. Items addressing participants' general preferences for patient participation in decision making are presented in Table 7.9.

Table 7.9: Items addressing participants' experiences of their most recent involvement in decision making and information provision

- The level of patient participation in the decision-making process
- The level of information that patients gathered from their physiotherapists about their LBP
- Whether the severity of pain affected patients' desire to be involved in making decisions
- How much physiotherapists encouraged patients to participate in making decisions about the management of their LBP
- How much physiotherapists encouraged patients to gather the information they wanted from them about LBP and its management
- Type/s of information received/given during the course of physiotherapy treatment

1. Types of treatment received/given during the course of physiotherapy treatment

Table 7.10 shows percentages indicating the congruence between the two groups of participants for their reported experience of type/s of information received/given during their most recent course of physiotherapy treatment. Apart from information about preventive management strategies, all results indicated a discrepancy between the levels of information of various types that participants reported had been given or received.

Table 7.10: Reported type/s of clinical information received/provided by participants during their most recent course of physiotherapy treatment

Reported type/s of information received/provided	% patients reporting receipt (n= 171)	% physiotherapists reporting providing (n=93)
Back pain in general	39	47
Spine biomechanics and healthy posture	26	73
Pain behaviour & management	36	63
Self-management programmes	67	82
Preventive management strategies	64	70
Common physiotherapy management for LBP	27	62
Others	8	5

2. Perceived experiences/ practice of patient participation and information provision during a most recent physiotherapy course

Table 7.11 presents p-values obtained from ordinal regression analysis to examine between groups differences, regarding their perceived experiences/practices during physiotherapy course indicated a very limited agreement between the two groups (see Table 7.11).

Physiotherapists reported lower patient participation in decision making and providing less encouragement of their patients to participate in decision making, whereas patients reported higher participation in decision making and receiving a little encouragement to participate. Patients also reported receiving less information than their physiotherapists claimed to give to their patients, although they reported more encouragement to gather information compared to the encouragement that physiotherapists reported having provided to their patients. In addition, most physiotherapists thought that pain severity influenced patients' preferences for participation in decision making, while most patients thought that this had no influence on their preferences for participation.

None of the independent variables was significantly explain between groups differences in their specific preferences for patient participant in decision making.

Table: 7.11: p-values identified with ordinal regression analysis to examine differences between groups of participants reported experience/practices of patient participation in decision making and information provision during their most recent physiotherapy course

Participants' reported experience of their most recent course of physiotherapy treatment	Amount of participation in decision making		Amount of encouragement received by/given to patients to participate in decision making		Amount of information gathered		Amount of encouragement received/given to patients in order to gather information		Influence of pain severity on patients' preferences for participation	
	PT	PH	PT	PH	PT	PH	PT	PH	PT	PH
Total number of respondents	114	90	113	90	115	90	115	90	110	90
Not at all or a little	31 **27%**	40 **44%**	20 **18%**	29 **33%**	20 **17%**	3 **3%**	19 **17%**	12 **13%**	48 **44%**	17 **19%**
Fair amount	33 **29%**	33 **37%**	22 **20%**	25 **28%**	34 **30%**	24 **27%**	27 **24%**	25 **28%**	32 **29%**	29 **32%**
A lot or a great deal	50 **44%**	17 **19%**	71 **63%**	35 **39%**	61 **53%**	63 **70%**	72 **63%**	53 **59%**	20 **18%**	44 **49%**
p-values	.001		.010		.002		.432		.001	

7.7 Discussion

This analysis has examined the similarities and differences between the preferences of physiotherapists and patients for patient participation in decision making and the preferences for receiving or giving information during the physiotherapeutic management of LBP. This section presents a summary of main findings, discusses these in relation to the existing evidence and provides insights to study implications to physiotherapy practice. Chapters five and six have discussed the methodology used and potential theoretical explanations of the findings and cultural influences are discussed in chapter eleven.

7.7.1 Summary and discussion of main findings

The results of this study show that physiotherapists and patients were in some disagreement regarding their preferences for patient participation in decision making. Physiotherapists demonstrated a strong general tendency to adopt a more paternalistic style of decision making, preferring patients to adopt a passive decisional role, though they were willing for patients to participate to some extent in decisions about their daily activities while not actually making these decisions for

themselves. In many ways this agreed with the views of patients, though patients who took part in this study did not adopt a totally passive position. In general, they demonstrated a preference for decisions to be made or controlled by physiotherapists, especially when 'important decisions' were being made. Despite this, they showed a preference in some situations for a sharing decisional role, especially when decisions were related to their daily activities, to the frequency of clinical visits, to their discharge plans and to whether they should pursue a home management programme following their visit to the physiotherapy department.

Although both parties expressed relatively more positive preferences for patient participation in their responses to general items, these preferences were weaker when they were asked to give opinions on who should make the decision about more specific components of care. Differences in both groups may be associated with acceptable levels of responsibility. Patients' views may indicate an interest in becoming part of the decision-making process while not being responsible for making decisions, a responsibility which it has been suggested may overwhelm and distress them (O'Connor, 1995) and therapists, functioning within a biomedical model of health care are likely to regard decision making as core to their clinical responsibilities with patients being treated as a passive components of the decision making process (Elwyn et al., 1999).

The similar discrepancy between both groups of participants' general and specific preferences may lie in the nature of the clinical decision. Bradley and colleagues (1996) suggest that preferences for patient participation must be assessed as scenario-based situations, because the severity of health conditions as well as contextual clinical circumstances were found to influence individuals' preferences for involving patients in making treatment decisions (Thompson et al., 1993, Ryan and Sysko, 2007, Müller-Engelmann et al., 2011). The management of LBP is comprised of a number of different aspects of care and these results show that both patients and therapists have different preferences for participation according to the element of care. Thus the 'scenario' referred to above can comprise not just the condition or clinical circumstance but also care itself.

Although some statistically significant differences in participants' reported preferences for information provision, the observed variations possibly did not indicate true disagreement, as the majority of participants in each group were compatible in supporting information giving and receiving during physiotherapy management for LBP. This general consensus across the two parties indicates general agreement in their perceptions of the importance of information provision during clinical physiotherapy encounters.

7.7.2 Discussion of main findings in relation to the literature

This is the first study examining similarities and differences between patients and physiotherapists in the field of LBP management; previous studies have mostly concerned decisions made in single clinical settings (Nomura et al., 2007, Burton et al., 2010), examining a wide range of medical conditions in one study (Deber et al., 2007, Murray et al., 2007a), while none has involved physiotherapy. Other studies have examined decisional conflicts between patients and physicians (Janz et al., 2004, LeBlanc et al., 2009); others have examined patients' perceived involvement in decision making during clinical consultations (Ruiz-Moral et al., 2006, Melbourne et al., 2011); and a third group of researchers has conducted separate studies to explore the preferences of the two parties (Murray et al., 2007b, Murray et al., 2007a).

In line with the current findings, the results of other studies suggest variations between the two parties. A review in 2001 by Montgomery and Fahey reports that the variations in preferences between clinicians and patients were not always consistent and suggests that such differences may relate to medical contexts. Their review involved studies covering a wide range of medical conditions including respiratory and cardiac illnesses, cancer and obstetrics and gynaecology. More recent studies confirm these differences but suggest rather more disagreement, which may be due to western practitioners moving towards a greater preference to involve patients in their care. McKeown and colleagues (2002) report a discrepancy in preferences for decisional control between medical residents (n=45) and patients with various medical conditions (n=92); the former wanted to give a greater role to patients, who in turn expected only a limited role in controlling decisions about their

care. A similar result was reported by Janz and colleagues (2004), who compared the preferences of 101 women with breast cancer for decisional control with their perceived experiences, as well as the agreement between patients and physicians regarding how decisions were made. The authors, who found a low level of agreement in participants' perceptions of how decisions were made, suggest that the observed disagreement may have resulted in part from the limited clinical communication between patients and physicians. This study examined only preferences for the overall decision, its findings were limited to well-educated and female patients and no information is given on how the level of clinical communication was evaluated. In a study with another professional group, Florin and colleagues (2006) investigated the level of agreement between nurses and patients admitted to inpatient wards and found that the nurses perceived the patients to prefer a more active contribution to decision making than was reported by the patients.

The present results have more in common with the earlier studies, in terms of the variations in the level of agreement between clinicians' and patients' preferences for patient participation in decision making. However, the current research differs in a number of respects, and some caution needs to be used when making comparisons. First, the findings of the above studies were limited to making an overall decision and did not examine preferences for individual aspects of the therapeutic process, while the current findings suggest that the aspects of physiotherapeutic management represent areas of debate between physiotherapists and patients with LBP. It is therefore essential that both parties understand the need to deliberate about them separately when making clinical decisions on LBP management, and particularly important for clinicians to be able to take the lead in this respect. Secondly, the above studies often involved heterogonous samples of patients with many different health conditions and this may contribute to further difficulty in extrapolating results to our study. Thirdly, approaches to examining the level of agreement were varied and finally, there was considerable variability in the demographic characteristics of the sample populations examined and there is some suggestion that this may will influence the level of agreement between patients and clinicians regarding their

perceived preferences for patient involvement in decision making (Melbourne et al., 2011).

Physiotherapists and patients who took part in the current study were in disagreement about their practice and experiences respectively during their most recent physiotherapy course to manage patients' LBP, with therapists indicating a limited participation by their patients during a physiotherapy course, while patients reported more participation.

One of the potential explanations is that the variations resulted from recruiting participants from different hospitals, which may have differed as the practice seemed to vary between settings. In addition, the time available for each visit and the level of communication between patients and physiotherapists may have had a role in these variations. A key challenge here is that each clinical setting is unique in its environmental circumstances. This suggests that the reported experiences may have varied according to differences in situational circumstances, including individuals' behaviours regarding SDM (Ruiz-Moral et al., 2006, Müller-Engelmann et al., 2011).

The disagreement between the two groups may also have been attributed to factors including the personal characteristics of patients and clinicians, the level of clinical communication and interaction, the nature of clinical decisions, individuals' outcome expectations, willingness and initial preferences for patient participation, and the clinical conditions, in addition to other situational and environmental circumstances (Montgomery and Fahey, 2001, Janz et al., 2004, Burton et al., 2010). These factors were discussed in chapters six and seven. The mismatch may also have resulted from clinicians' attitudes to implementing patient participation in decision making, with clinicians providing much less opportunity that patients wanted. Various reasons have been discussed above but one additional reason may be that clinicians may adapt their attitude to patient participation in decision making according to patients' perceived participative behaviour during clinical encounters; that is, to whether they consider the patients to be 'self-reliant' or 'clinician-reliant' (Makoul, 1998, Müller-Engelmann et al., 2011). Yet it is unknown how patients and physiotherapists

perceived patient participation and information provision during the actual physiotherapy encounters.

7.7.3 Implications for practice

Evidence suggests that considering patients' needs and concerns when making decisions related to their care is important in achieving patient satisfaction and adherence to interventions(O'Connor, 1995, Robinson and Thomson, 2001, Jahng et al., 2005). This study indicated a strong call for changing physiotherapists' practice in Saudi Arabia from the biomedical model of decision making into more collaborative, bio-psychosocial model. This type of clinical interaction can reduce potential decisional conflicts as patients feel engaged in the decision making process and provided with the information they want and need (O'Connor, 1995, LeBlanc et al., 2009). One way may be through pre-registration training programs that increase physiotherapists' knowledge and understanding about patients' ethical and clinical rights to be involved in making decisions related to their health and the potential value of patient involvement in increased satisfaction and better clinical outcomes. Patient centred care, as a component of evidence based practice, needs to be incorporated at both pre- and post-registration learning. Such a "change" in physiotherapy practice can be supported by changing or establishing clinical guidelines that take these rights and benefits into consideration. In addition, public educational programs are required to raise people awareness about the importance of patient participation in decision making and finding practical approaches to improve clinical communication between patients and clinicians. However and despite some government approaches that are beginning to encourage related concepts such as self-management, the diversity in health systems in Saudi Arabia and the pre-dominance of the biomedical model of care at practice level may challenge this move into SDM model.

7.7.4 Conclusion

The current study, set in Saudi Arabia, examined similarities and differences between physiotherapists and patients during the physiotherapeutic management of non-specific LBP. As to their preferences for 'who should make decisions' about managing

LBP, both groups of participants preferred these key decisions to be controlled predominantly by physiotherapists; however, patients preferred to give a more active or shared role in this process than physiotherapists wanted them to have. All participants reported higher levels of consensus in their preferences for information provision. In order to take this work further, studies are required to examine and identify factors that may explain why patients and physiotherapists prefer certain decisional roles for patients when making treatment decisions, how both parties prefer to use clinical information and how they tend to resolve clinical conflicts on disagreed decisions.

Chapter Eight

In-depth examination of patients' and physiotherapists' views and reasons for their preferences for patient participation in the management of Non-specific low back pain: the development of focus group topic guides and analysis

8.1 Introduction

Following the cross-sectional questionnaire studies, two separate focus group studies (reported in chapters nine and ten) were undertaken to explore respectively physiotherapists' and patients' perceptions of patient participation in decision making and information provision. This second phase of the current research used mixed methods and was designed to complement the findings of the cross-sectional studies. Methodological considerations related to the research design were highlighted and discussed in Chapter two. The present chapter, in two sections, describes first the development of the probes used in the topic guide of each focus group study, then the procedure followed in analysing the data.

8.2 Development of the topic guides

As explained in Chapter three, the aim of the qualitative phase of the current research, set in Saudi Arabia, was to provide in-depth understanding of physiotherapists' and patients' perceptions and views of patient participation in decision making and information provision during the management of non-specific LBP. While the findings of the cross-sectional questionnaire studies were valuable in indicating trends among the preferences reported by the participants (presented in chapters five to seven), it remained unclear how precisely patient involvement in decision making was perceived by physiotherapists and patients; nor did these studies explain why participants tended to adopt their stated preferences. In order to complement the questionnaire findings, the focus group studies were designed to explore and record participants' opinions regarding patient involvement in various

aspects of physiotherapy decision making, as well as their perceptions of reasons for this participation and information provision, of difficulties associated with this, of types of information that the parties would prefer to exchange (or not), of reasons for gathering or giving clinical information and of methods of doing so.

The aims of the focus group studies were to examine in depth:

1. patients' experiences of decision making and information provision during recent physiotherapy treatment programmes;
2. physiotherapists' usual practice with respect to decision making and information giving when managing patients with non-specific LBP;
3. patients' and physiotherapists' views on patient participation in making treatment decisions;
4. patients' and physiotherapists' views regarding the types, modes of delivery and amount of information they wanted to gather or provide in relation to the management of their (patients') LBP.
5. patients' and physiotherapists' views of potential difficulties and their reasons for adopting certain preferences for decision making and information provision.

The numbers assigned to the aims above identify them in Tables 8.1 and 8.2 below, where they are related to focus group probes.

8.2.1 Constructing the topic guides

Before conducting the focus group studies, the researcher was unable to identify any information on similar work examining in depth the views and perceptions of physiotherapists and patients with LBP of various aspects of patient involvement in physiotherapy decision making. Furthermore, the trends among the overall preferences for patient involvement in physiotherapeutic care in Saudi Arabia were unknown before the conduct of the cross sectional studies. Therefore, the preliminary findings of the phase one studies, in addition to the relevant literature,

were used to underpin the design of the probes and the structure of the topic guides. This section provides details of the development of their contents and structure.

8.2.1.1 Use of relevant literature to underpin the design of the topic guides

The literature on preferences for patient participation in decision making and information provision is examined in chapter two. This subsection considers in detail two types of study which were used to underpin the design of the focus group topic guides: those concerned with the conceptual framework of preferences for patient participation in decision making and qualitative studies examining patients' perceptions and expectation of LBP management.

- **Conceptual frameworks of preferences for patient participation**

The conceptual and theoretical underpinning of the examination of patient involvement in decision making and preferences for this involvement are presented in chapter two. The theoretical models, in addition to current competencies of SDM, identified decision making and information provision as key distinct measurable dimensions (Ende et al., 1989, Flynn et al., 2006). The design of the focus group topic guides was therefore based on these two main domains, which structured the overarching questions and the probes used.

The SDM competencies (chapter two) involved three main areas of clinical decision making in relation to patient involvement: defining preferred decisional roles, deliberation on treatment choices and the exchange of clinical information between patients and clinicians (Elwyn and Miron-Shatz, 2010). These competencies were used in constructing an overarching framework for the probes in the topic guides. To illustrate, the probes involved examining in depth participants' perceptions and views on providing patients with treatment options/choices; on how treatment options are often discussed between patients and physiotherapists during physiotherapy settings; on the perceived role of each party in such discussions; and on types of clinical information and ways to gather this information and give it to patients.

- **Perceptions and expectations of managing low back pain**

Further to reviewing the current conceptual basis and theoretical models of patient involvement in decision making and information provision, studies that employed qualitative methods to examine perceptions of low back pain management were also reviewed. The literature identified a number of key themes of patient perceptions of aspects of their LBP management, including their experiences of managing their LBP, the concept of 'patient-centeredness' and their expectations of the treatment provided to manage their LBP.

As mentioned in chapter two of this thesis, research into patient involvement in physiotherapy decision making is limited. In particular, preferences of physiotherapists and patients with LBP for patient participation in decision making have not been identified. Cooper and colleagues (2008) used semi-structured interviews with patients with chronic LBP to identify their perceptions of the concept of 'patient-centeredness' in physiotherapy. They identified two distinct domains: patients' desire to participate in decision making and to share clinical information with physiotherapists. Other domains identified included communication, individualizing care, trust of the physiotherapist and organizing treatment sessions. The sample employed in this UK-based study was relatively small (n=25) and dominated by female patients. Nevertheless, its findings support the choice of 'patient participation in decision making' and 'information provision' as the two main domains in the construction of the topic guide, as indicated in the conceptual basis and theoretical models of patient involvement in decision making. The other themes identified were concerned with aspects of the physiotherapeutic management of LBP as perceived by patients. These were included in the probes and adapted to match the five aims of the focus group studies as listed above.

Numerous recent studies, reviewed in chapter two of this thesis, have addressed patients' expectations of the management of their LBP (Slade et al., 2009, Cooper et al., 2008, Liddle et al., 2007, Verbeek et al., 2004). They report a variety of perceptions and experiences: 1) patients' needs and expectations regarding the individualizing of their treatment plans through proper communication, supervision

and ongoing support from their care-providers; 2) patients' expectations and need to be heard and understood by their care-providers; 3) patients' desire to be informed about therapeutic approaches to managing their LBP and establishing a good level of clinical interaction with their therapists (deliberation phase of SDM). In addition, Cooper and associates (2009) examined chronic LBP patients' views of the extent to which physiotherapy helped them to self-manage their condition following discharge. Patients reported their need for self-management support after being discharged from physiotherapy services. None of the above studies aimed to identify reasons for adopting particular preferences for patient decisional roles or desires for information provision; nor did they elicit physiotherapists' perceptions. Moreover, while they adopted the interview method, only the work by Liddle and colleagues (2007) used focus groups and only Cooper and associates (2008 and 2009) conducted their studies within the physiotherapy context.

Among the important themes emerging from these studies concerning patients' perceptions of therapeutic approaches to managing their LBP were:

- Patients being involved in treatment decisions (Cooper et al., 2008, Verbeek et al., 2004, Liddle et al., 2007)
- Gathering information from practitioners (Cooper et al., 2008)
- Giving priority to the management of pain relief (Liddle et al., 2007, Slade et al., 2009, Verbeek et al., 2004)
- Convenience of the treatment (Liddle et al., 2007, Slade et al., 2009, Cooper et al., 2008)
- Improved communication with practitioners (Cooper et al., 2008, Slade et al., 2009)
- Patients' need to self-manage their LBP after discharge from physiotherapy services (Cooper et al., 2009).

While the abovementioned studies provide some indications of perceptions regarding LBP management within a number of western societies, it is notable that the cultures and health systems concerned are different from those of Saudi Arabia; the

generalizability of the probes used and of the themes and topics discussed in these qualitative studies is likely to be limited, since these studies do not provide in-depth information about perceptions of the concept of patient participation and information provision or about reasons for adopting certain preferences. However, these studies identify a number of themes which provided a general guide to structuring the probes and topic guides for the current focus group studies. The reported themes were regarded as areas to be merged together to develop the probes, which are presented in chapter nine and ten.

8.2.1.2 Use of the preliminary results of the cross-sectional studies of the current research to underpin the topic guide

The questionnaires (see Appendix 4.10 and 4.11) used in the cross-sectional phase of the current research contained items examining participants' preferences for patient participation in decision making at three levels: 1) general views of patient participation in decision making; 2) preferences for who should make decisions on various aspects of physiotherapy (patients' daily activities, home programmes, amount of clinical supervision, frequency of physiotherapy sessions, follow-up appointments, discharge plan and type of treatment); 3) overall preferences for who should make decisions regarding the management of LBP in physiotherapy. In addition, participants were asked to report their preferences for information provision (receiving or giving) and to report their most recent experiences of patient involvement in managing LBP in physiotherapy.

The topic guide was designed after preliminary analysis of the questionnaire results (chapters five, six and seven), to ensure that the quantitative and qualitative methods were employed together within a sequential explanatory approach. As explained in chapter three, it was anticipated that the qualitative phase would explain the findings of the cross-sectional phase, which would inform the design of the focus group topic guides.

The preliminary analysis of LBP patients' preferences for involvement in decision making showed that they tended to prefer more passive roles, especially in making decisions on clinical matters, but a cross-sectional questionnaire-based study was not able to identify the reasons for this preference. In contrast, patients' desires to gather clinical information about their LBP was greater, but it was unclear whether they would use such information to improve their condition and if so how. As for the physiotherapists, they showed a predominant tendency to prefer a more paternalistic style of decision making, although they believed that patients could participate in making decisions concerning their daily activities. The desire of physiotherapists to give clinical information was also greater than their preference for patient participation in decision making; however, it was unknown whether they intended such information to facilitate patients' participation in managing their LBP. In addition, preferences for making decisions about discharge from physiotherapy and frequency of treatment sessions were found to differ strongly among the two groups of participants. Finally, it was noticed that patients wanted a more active or sharing role in making decisions about their daily activities.

The above results indicated several points to be taken into consideration when designing the topic guides for the focus group studies. There appeared to be a need for greater clarification and a deeper understanding of:

- Reasons for adopting certain preferences when making treatment decisions about managing LBP.
- Views on decisions about discharge from physiotherapy, frequency of treatment sessions and patient daily activities; and on what should be done when a decisional conflict arises during physiotherapy.
- Reasons for a desire to give or receive clinical information and how physiotherapists and patients use this information during physiotherapy.

The results of the cross-sectional studies indicated that the preferences of both physiotherapists and patients were significantly associated with patients' age, education level and severity of LBP and with physiotherapists' experience, workload

and type of hospital. These findings were taken into account when selecting the samples to participate in the focus group studies.

8.2.2 Contents of the topic guide

The focus group topic guides were constructed to take account of the study aims, the relevant literature and the preliminary results of the questionnaire studies. As explained above, patient participation in decision making and information provision formed the two key domains of the guides (Bowling, 2009, Silverman, 2011, Krueger and Casey, 2009), whose construction followed the questioning route described by Krueger and Casey (2009). This involved categorising the probes as opening, introductory, transition, key and ending probes. In order to meet the aims of the focus group studies, the probes covered the following topics in each domain.

The decision making domain of each topic guide included probes about the following: 1) perceptions of previous clinical experiences of decision making as part of the physiotherapeutic management of LBP; 2) perceptions of the concept of patient participation in decision making, including its benefits or shortcomings; 3) views on patients being provided with treatment options/choices on visit frequency, discharge, amount of supervision and self-management; 4) reasons for adopting certain preferences for patient participating in decision making; 5) difficulties and facilitating factors for patient participation in decision making; and 6) perceptions of situations of conflict over clinical decisions.

The information provision domain of the topic guide included probes about the following: 1) perceptions of previous clinical experiences of information gathering/giving in LBP physiotherapy; 2) reasons for preferring certain ways of gathering, receiving or delivering certain types and amounts of clinical information during LBP management in physiotherapy settings; 3) reasons for adopting certain preferences for gathering, receiving or giving clinical information about managing LBP; 4) difficulties and facilitating factors in the gathering, receiving or giving of clinical information about managing LBP.

Tables 8.1 and 8.2 list the probes and questions to be used respectively in the patients' and therapists' focus group studies. The right-hand column relates the probes to the five aims of this phase of the study, as listed in section 8.2 above.

Table 8.1: Topic guide for the patients' focus group study

Opening question (Aims: breaking the ice and engaging participants**)** - Can you tell me how you ended up receiving physiotherapy treatment? Are you satisfied with the treatment you received? Why? Why not? **Transition question (Aims:** introducing the topic and exploring perceived experiences of physiotherapy settings**)** - Did you participate with your physiotherapist in choosing your physiotherapy treatment for your back pain?	
Key areas: Overarching views of patient participation in making treatment decisions and information gathering	
Domain 1: Patient participation in decision making	
Probes	**Related aims of this phase**
1) Perceptions of patients' experiences of decision making during recent physiotherapy treatment programmes	**1**
2) Views of the appropriateness of patient participation in making treatment decisions, including providing patients with treatment options	**2**
3) Views of making decisions on patient discharge from physiotherapy services	**2**
4) Views of situations when decisional conflicts arise	**2**
5) Reasons for adopting certain preferences for patient participation in decision making	**5**
Domain 2: Information provision	
Probes	**Related aims of this phase**
1) Perceptions of patients' experiences of information gathering/exchanging during recent physiotherapy treatment programmes	**1**
2) Views about the types, amount and mode of delivery in information gathering relating to the management of patients' LBP; including their perceptions about physiotherapist's role in information giving, and reasons	**4**
3) Perceptions of difficulties with information gathering	**5**
Closing question: Would anyone like to add anything? **Conclusions and thanks**.	

Table 8.2: Topic guide for physiotherapists' focus groups

Opening question (Aims: breaking the ice and engaging participants**)** - In your opinion, to what degree can physiotherapy help patients with LBP? **Transition question (Aims:** introducing the topic and exploring perceived experiences of physiotherapy settings**)** - Do your patients participate with you in making treatment decisions?	
Key areas: Overall views of patient participation in making treatment decisions and gathering information	
Domain 1: Patient participation in decision making	
Probes	**Aims related to questions**
1) Perceptions of their usual practice of decision making when managing patients with non-specific LBP	**2**
2) Perceptions of the appropriateness of patient participation in decision making, including potential benefits and shortcomings	**3**
3) Views on patients being provided with treatment options/choices	**3**
6) Perceptions of situations when decisional conflicts arise between patients and physiotherapists	**3**
4) Reasons for adopting certain preferences for patient participation in decision making	**5**
Domain 2: Information provision	
Probes	**Related aims of this domain**
1) Perceptions of previous clinical experience of information giving as part physiotherapy process to manage LBP.	**2**
2) Reasons for adopting certain preferences for giving clinical information about managing patient LBP	**5**
3) Views about the types, amount and mode of delivery in information giving relating to the management of patients' LBP in physiotherapy settings	**4**
4) Difficulties and facilitating factors for giving clinical information about managing LBP	**5**
Closing question: Do you think that applying this type of practice (involving patients in treatment decisions) needs special skills? If so, what are they? **Conclusions and thanks**: Would anyone like to add anything?	

8.3 Testing the topic guide

The topic guides were checked thoroughly and repeatedly by the researcher for their content validity, taking into account the aims of the study, the relevant literature and the preliminary results of the questionnaire surveys. The structure and content of the guides went through a number of refining stages (Krueger and Casey, 2009), aiming:

- for coverage of the main areas, i.e. perceptions of patient involvement in decision making and information provision,
- for simplicity and clarity in the wording of the probes,
- for short, open-ended and one-dimensional probes, and
- to ensure the flow of the questioning route used.

In addition, two separate testing sessions were conducted, aiming to examine the probes, as well as enhancing the researcher's ability to probe deeply into participants'

views of patient involvement in decision making and information provision (Krueger and Casey, 2009). Hence, both sessions were regarded as practice runs, prior to conducting the focus group sessions.

- **Testing Session 1 (in the UK)**

  - **Aim**

This session aimed to examine the content and structure of the patients' topic guide for clarity and suitability, in addition to enhancing the researcher's ability to manage the focus group sessions.

  - **Subjects**

A simulated patient sample (n=4) was employed, comprising other researchers with academic backgrounds.

  - **Procedure**

Participants were identified and approached by the researcher. They were given information sheets (CD Appendix 17) as well as verbal explanations of the study aims, the procedure and what the session would entail.

At the focus group session, participants were informed about their assumed role as patients with LBP. They were encouraged to interact and to express their views freely during the session, which lasted approximately one hour. Up to two thirds of the probes were discussed with the participants during the session.

  - **Results and conclusion**

The probes were found to be suitable to examine in depth participants' views about the topic of the study. No amendments to the contents of the topic guide were suggested by participants. However, their comments indicated that the researcher required more practice in easing the flow of the discussion and that she should avoid using technical terms when examining patients' views, so that they would be able to understand and interact.

- **Testing Session 2 (in Saudi Arabia)**

  - **Aim**

The second session aimed to examine the content and structure of the topic guide for the physiotherapists' focus group, to ensure its clarity and suitability for physiotherapy practice in Saudi Arabia; in addition it aimed to enhance the researcher's ability to manage the focus group sessions.

  - **Subjects**

A simulated physiotherapist sample (n=8) was composed of final-year physiotherapy students at a University in Riyadh.

  - **Procedure**

Potential participants were identified by a senior lecturer and approached by the researcher. They were given information sheets (CD Appendix 17) as well as verbal explanations of the study aims and procedure, and what the session would entail.

At the session, the language used was primarily English. Participants were informed of their assumed role as physiotherapists treating LBP; they were encouraged to interact and to express their views freely during the session, which lasted for approximately one hour. All of the probes were discussed with the participants.

  - **Results and conclusion**

The probes were found to be suitable to examine in depth the views of physiotherapists about the topic of study. Participants suggested no amendments to the contents of the topic guide, but they did suggest that the researcher would need to engage the focus group members at the beginning of the session.

8.4 Data analysis

As with other qualitative methods, the analysis of focus group data requires an objective and rigorous examination of the detailed constructions (Creswell, 2009, Webb and Kevern, 2001, Silverman, 2011, Sim and Snell, 1996). Methods of analysing qualitative data are typically varied (Corbin et al., 2008, Silverman, 2011); these

include ethnographic, narrative, thematic or content analysis in addition to framework analysis (Corbin et al., 2008, Silverman, 2011, Cooper et al., 2008, Bowling, 2009). The analysis of qualitative data from the current study was based on framework analysis as reported by Ritchie and Spencer (1994), since it comprises systematic and sequential steps to provide a comprehensive, transparent and rigorous management of the data (Silverman, 2011, Krueger and Casey, 2009, Ritchie and Spencer, 1994). This section relates the process of analysing the focus group data to the study aims and to the topic guides.

As elucidated above in this chapter, the second phase of the research was designed to complement the findings of the cross-sectional phase and to meet the aims presented above. Framework analysis was employed to identify in-depth information related to patient participation in decision making and information provision, including reasons, concepts, difficulties and facilitating factors as perceived by participants (van Teijlingen, 2003, Krueger and Casey, 2009, Silverman, 2011, Rabiee, 2004).

8.4.1 Data analysis tool

The analysis was carried out using the NVivo software (version 8) (Krueger and Casey, 2009, Silverman, 2011). The justification for this choice is discussed in section 4.4.4.1.

8.4.2 Data analysis process

The analysis of focus group data comprised the following five stages: familiarising the researcher with the data; applying a systematic identification of codes; recognizing emerging themes; indexing and charting these themes; and examining the analytical framework. These stages were guided by the research aims, by the probes and the topic guide and by the preliminary findings of the questionnaire phase (Rabiee, 2004, Krueger and Casey, 2009, Cooper et al., 2008).

1. Familiarization stage

The aim of the familiarization process was to gain an understanding of the data stream (Silverman, 2011). The researcher began to become familiar with the contents

of the transcripts when moderating the focus groups, then by listening repeatedly to the recordings, transcribing them verbatim immediately after each focus group was finished and translating each transcript from Arabic into English. This facilitated her observation of the flow of the data, allowing her to review its contents, to discover potential opportunities to generate patterns and to find common ideas (Bowling, 2009, Krueger and Casey, 2009).

2. Codifying synergic concepts

Following the familiarization stage, synergic concepts were codified in three cycles:

The preliminary cycle involved initial attempts at grouping the common ideas found in all transcripts. In order to ensure the researcher's ability to codify these, one full transcript was randomly selected and the researcher assigned codes, which were then tested against the coding of an independent researcher who was expert in analysing qualitative data and was able to review the study aims before commencing the testing procedure. The aim was to ensure that the researcher's coding had followed a correct procedure of the kind often applied by qualitative researchers. The researcher and the independent reviewer went through the whole transcript independently to assign codes, before meeting to compare their results and to discuss similarities and dissimilarities. The testing procedure revealed 100% agreement between the researchers.

The purpose of **the intermediate cycle**, which involved all transcripts, was to discover and identify themes and to consolidate concepts. Sentences that corresponded with common ideas were classified under codes, whose characteristics were defined and labelled as subcategories and then grouped into larger categories (themes) with distinctive features.

The final cycle involved revisiting the full texts and the codes generated earlier, in order to reduce and refine these, to ensure the logical relevance of meanings and to examine them for redundancy, repetition and overlapping.

- **Rigour**

The rigour of the current study was achieved first by validating the topic guide and secondly by following a rigorous analytical approach. Checking the quality and credibility of findings is essential to ensure the rigour of any analysis (Shenton, 2004, Silverman, 2011, Whittemore et al., 2001). However, differences in the paradigmatic orientation of quantitative and qualitative methods leads to differences in testing their validity and reliability (Bowling, 2009): whilst quantitative researchers tend to examine certain criteria such as reliability and validity, qualitative ones prefer to assess the credibility and trustworthiness of their findings (Whittemore et al., 2001, Shenton, 2004).

Verification of the codes was carried out in two stages. Stage one involved checking 25% of the main themes against the judgements of an independent expert in qualitative research. This independent researcher went through all the transcripts, being provided with a list of the codes and their definitions. One major theme was randomly selected: physiotherapists' views of patient participation in decision making. Deliberations about the headings, subheadings, codes and definitions were incorporated to ensure the transparency of the analytical framework. The deliberation session revealed general agreement on the codes, but around 20% of them required further explication of the definitions given (Whittemore et al., 2001). Accordingly, the whole analytical framework was subjected to another refining cycle before the second verification process commenced.

Stage two involved checking 30% of each of the domains identified. Thus, themes and codes were randomly selected and checked over four sessions. Another independent researcher volunteered to assess the scrutiny of the analysis. Study aims, conceptual framework and transcript contents were explained to the independent researcher prior to an examination of the findings for reliability. At the beginning of each session, each researcher had a separate and full copy of the domain being examined. A list of categories, subcategories and definitions was reviewed and 30% of the document was randomly selected. Both researchers went through the selected codes and assessed their relevance to the categories as well as their definitions (Barbour, 2001,

Whittemore et al., 2001). Whenever a disagreement occurred, the two assessors negotiated until they had achieved full agreement.

3. Data indexing and charting

An index of the categories and subcategories was created in order to form the thematic framework of the data. Indexes of data from the patients' and physiotherapists' focus groups and their relevance to the topic guide are presented in Tables 9.4, 9.5, 10.4 and 10.5 in Chapters nine and eleven respectively. Each index so created was applied to the original texts. Transcripts were then reread and passages were examined for appropriateness to indexing.

Following the indexing procedure, data were placed into charts containing definitions, with headings and subheadings relevant to the research question. The charts (in tables), which were kept separate from the original texts, were revised for relevance, clarity and sequence. Indexing and charting were guided by the topic guide and the research question.

4. The analytical framework

The output of the analysis revealed two main domains: the views of subjects (physiotherapists and patients with LBP) on patient involvement in decision making and on information provision. Diagrams representing this analytical framework for the patient and physiotherapist focus groups respectively are presented in Figures 9.1 and 10.1 in Chapters nine and ten. Each domain involved the views of both patients and physiotherapists; therefore, the data generated were distinguished into four main areas, covering the opinions of each group concerning participation in decision making and information provision respectively.

Chapter Nine

Study 4: An in-depth examination of patients' experiences of physiotherapy for non-specific LBP, their perceptions of the appropriateness of participation in decision making and information provision, and reasons for these preferences

9.1 Introduction

This chapter reports study four of the current research, in which focus groups were used to investigate patients' experiences of physiotherapy for non-specific LBP, their perceptions of the appropriateness of participation in decision making and information provision, and reasons for these preferences. Justifications of the use of this qualitative method, the selection of the study sites and the sampling technique are all given in chapter three, while the development and testing of the focus group topic guide and the analysis of the results are all described in chapter eight.

9.2 Aim

The current study convened focus groups of patients with non-specific LBP with the aim of examining in depth:

1. experiences of decision making and information gathering/exchanging during recent physiotherapy treatment programmes.
2. preferences and views regarding patient participation in making treatment decisions.
3. preferences and views regarding the types, modes of delivery and amount of information they wanted to gather in relation to the management of their LBP.
4. reasons for adopting these preferences.

9.3 Method

9.3.1 Study Design

Seven focus groups of patients with LBP (n=27; 2-6 patients in each group) were conducted from December 2010 to January 2011 in Riyadh, using a semi-structured interview technique with open-ended questions.

9.3.2 Participants

A purposeful sample was recruited, comprising female and male patients with non-specific LBP attending the physiotherapy out-patient services of the three hospitals. The sample was stratified in terms of age, gender and educational level.

Three hospitals in Riyadh (civilian, military and private) were randomly selected from a total of eighteen hospitals located in that city. The physiotherapy departments of these hospitals had separate rooms that could be used for the focus groups, where the confidentiality of participants was assured during their conduct.

Inclusion criteria

Participants were included if they were adult patients aged 18 years and above who had been referred to physiotherapy out-patient services with non-specific LBP, with or without nerve root involvement (Koes et al., 2006).

Exclusion criteria

Patients were excluded from participation if they refused to be audio-taped during the focus groups or if they had any known "red flag" conditions such as tumour, fracture, infection or cauda equine syndrome (Fritz et al., 2003, Hay et al., 2008).

9.3.3 Ethical Approval

Ethical approval was obtained from the Ethics Committee at King's College London; study number BDM/09/10-87 (Appendix 9.1). Local agreements were obtained from the health facilities involved, prior to recruiting participants.

9.3.4 Procedure

9.3.4.1 Recruitment procedure

- **Study site**

The researcher approached each selected hospital by contacting the head of its physiotherapy department, through the office telephone, by e-mail, invitation letter (Appendix CD Appendix 18) or in person. She paid a preliminary visit to each potential physiotherapy department to provide further explanations and to request support in recruiting patients. Departments were provided with information sheets (CD Appendix 17) and consent forms (CD Appendix 19) in envelopes. Managers were also asked for permission to use rooms located within their departments to conduct the focus groups.

- **Participants**

During the preliminary visit, managers, clinical supervisors and staff physiotherapists were asked to assist in accessing patients with LBP receiving physiotherapy programmes in their departments. The inclusion criteria for patients were explained to the reception staff and to the staff physiotherapists treating them, who would be involved in identifying patients to the researcher.

Potential participants were first approached by physiotherapy staff or reception staff. They were provided with invitation letters, attached to information sheets (CD Appendix 17) and consent forms in envelopes (CD Appendix 19). The information sheet included an invitation to participate in this research project, information about the importance of the topic, details of how the focus groups would run and of what was expected from each participant during the focus groups. Subjects were advised that they should participate only if they chose to do so and that they could withdraw at any time without giving a reason. They were assured that their participation was anonymised. Information sheets and consent forms for patients were translated into Arabic, following the procedure outlined on page 171. Patients who agreed to participate were asked to contact the researcher directly to provide her with their

contact details, so that information about the venue and time of the focus group could be provided.

Potential participants who were illiterate had to have the study aims and procedures explained to them by the researcher; all patients were informed of what participation would entail and how to volunteer. They were able to take information sheets and consent forms home to discuss them with their families and friends and to ask questions if they needed to do so.

Throughout recruitment, the researcher paid regular visits to the sites in order to speak to potential participants as necessary and to respond to their questions.

9.3.4.2 Focus group procedure

Seven focus group sessions were conducted, three for male and four for female subjects, the sexes being separated for cultural reasons in Saudi Arabia. All focus groups were conducted in Arabic. The sessions were held in gymnasiums located within each department and were suitable to ensure the confidentiality of the discussions. The aim was to provide informal environments for the discussion, in a familiar situation in which participants were likely to be more comfortable. Refreshments were provided. Sessions lasted between 60 and 90 minutes and were all audio-taped, with subjects' agreement (McCaffrey et al., 2007).

Each session was conducted by a facilitator (the researcher) and a co-facilitator (Krueger and Casey, 2009). The role of the facilitator was to ensure a comfortable environment, to balance the depth and coverage of the topic, to facilitate interaction among participants, to ensure that everyone participated and to guide the discussion, while the co-facilitator was responsible for taking notes throughout the discussions, operating and checking the recording devices and helping with refreshments (Krueger and Casey, 2009, Kitzinger, 1995). The co-facilitator was a graduate female physiotherapist with research experience, whose contribution was standardized so that it was identical for each group. The facilitator explained the aim and conduct of the sessions to her before the groups met.

On arrival, potential focus group participants were provided with a further copy of the project information sheets and consent forms to sign before they commenced their participation. Immediately before each group discussion began, participants were requested to provide demographic details, including their age, gender, level of education and occupational status. They were welcomed, verbally advised that they should participate only if they chose to do so and reassured that they could withdraw from the focus group process at any time without giving a reason. They were also assured that their participation would be anonymised.

The confidentiality of the discussion was emphasised at the beginning of each session. Participants were informed that the information they provided would be kept strictly confidential in locked storage at King's College London. The discussions were guided by the topic guide (see Table 9.1) and only audio-taped, as videotaping would have been culturally unacceptable. Participants were informed that once the contents of the discussions had been transcribed, the audio-taped materials would be destroyed. At the end of each session, participants were thanked for their participation and the co-facilitator gave an oral summary of the discussion. Each participant received a small token of appreciation: a gift card for 50 riyals (approximately £9).

Table 9.1: Topic guide for the patients' focus group study

Opening question (Aims: breaking the ice and engaging participants**)** - Can you tell me how you ended up receiving physiotherapy treatment? Are you satisfied with the treatment you received? Why? Why not? **Transition question (Aims:** introducing the topic and exploring perceived experiences of physiotherapy settings**)** - Did you participate with your physiotherapist in choosing your physiotherapy treatment for your back pain?	
Key areas: Overarching views of patient participation in making treatment decisions and information gathering	
Domain 1: Patient participation in decision making	
Probes	**Related aims of this phase**
1) Perceptions of patients' experiences of decision making during recent physiotherapy treatment programmes	**1**
2) Views of the appropriateness of patient participation in making treatment decisions, including providing patients with treatment options	**2**
3) Views of making decisions on patient discharge from physiotherapy services	**2**
4) Views of situations when decisional conflicts arise	**2**
5) Reasons for adopting certain preferences for patient participation in decision making	**4**
Domain 2: Information provision	
Probes	**Related aims of this phase**
1) Perceptions of patients' experiences of information gathering/exchanging during recent physiotherapy treatment programmes	**1**
2) Views about the types, amount and mode of delivery in information gathering relating to the management of patients' LBP; including their perceptions about physiotherapist's role in information giving, and reasons	**3 & 4**
3) Perceptions of difficulties with information gathering	**3**
Closing question: Would anyone like to add anything? **Conclusions and thanks**.	

9.4 Analysis

Framework analysis was used to analyse data derived from the focus groups (Ritchie and Spenser 1994). A detailed explanation of this analytical approach is provided in chapter eight. The NVivo software program (version 8) was used to categorize the codes, as described in the same cahpter.

9.5 Results

This section presents participants' demographic characteristics and the main themes and sub-themes obtained from the focus groups.

9.5.1 Demographic characteristics

Of 42 invited subjects, 27 patients with LBP agreed to participate and attended one session each. The number of participants in each group is represented in Table 9.2, while the demographic characteristics of the participants are presented in Table 9.3.

Participants were predominantly young or middle aged, with an intermediate or college level of education and employed in professional work. Approximately equal numbers of participants were recruited from each of the three hospital settings.

Table 9.2: Number of participants in each focus group

Patient focus group	Number of participants
1 (female)	**5**
2 (male)	**6**
3 (male)	**3**
4 (female)	**4**
5 (male)	**5**
6 (female)	**2**
7 (female)	**2**

Table 9.3: Participants' demographic characteristics (n=27)

Demographics	Participants (n=27)	%
Age		
18-24	5	19
25-34	9	33
35-44	4	15
45-54	8	30
55+	1	4
Gender		
Male	14	52
Female	13	48
Educational Level		
Primary	2	7
Intermediate/secondary	9	33
College/university	13	48
Postgraduate	2	7
Illiterate	1	4
Occupational Status		
Unemployed	2	7
Manual work	5	19
Housewife	5	19
Professional	11	41
Student	2	7
Retired	2	7
Hospital Type		
Military	7	26
Civilian (university)	11	41
Private	9	33

9.5.2 Focus groups findings on participants' experiences of physiotherapy for non-specific LBP, their perceptions of the appropriateness of participation in decision making and information provision, and reasons for these preferences

The patient focus group study aimed to examine participants' experiences of physiotherapy for non-specific LBP, their perceptions of the appropriateness of participation in decision making and information provision, and reasons for these preferences. The next two sections report the views of participants in the seven focus groups on the following:

- Their experiences of physiotherapy for non-specific LBP, their perceptions of the appropriateness of participation in decision making and information provision, and reasons for these preferences
- Their views about the types and amount of information they wanted to receive, the mode of delivery, difficulties in gathering it and reasons for their preferences.

The resulting framework analysis identified themes and subthemes related to the topic guide, as presented in Figure 9.1. All codes are presented in tables listing the main source of the focus group (original transcripts), themes and sub-themes identified and line numbers within the original transcripts (see CD Appendix 20 for examples of the identified codes). All the obtained transcripts are presented in an attached CD to this thesis.

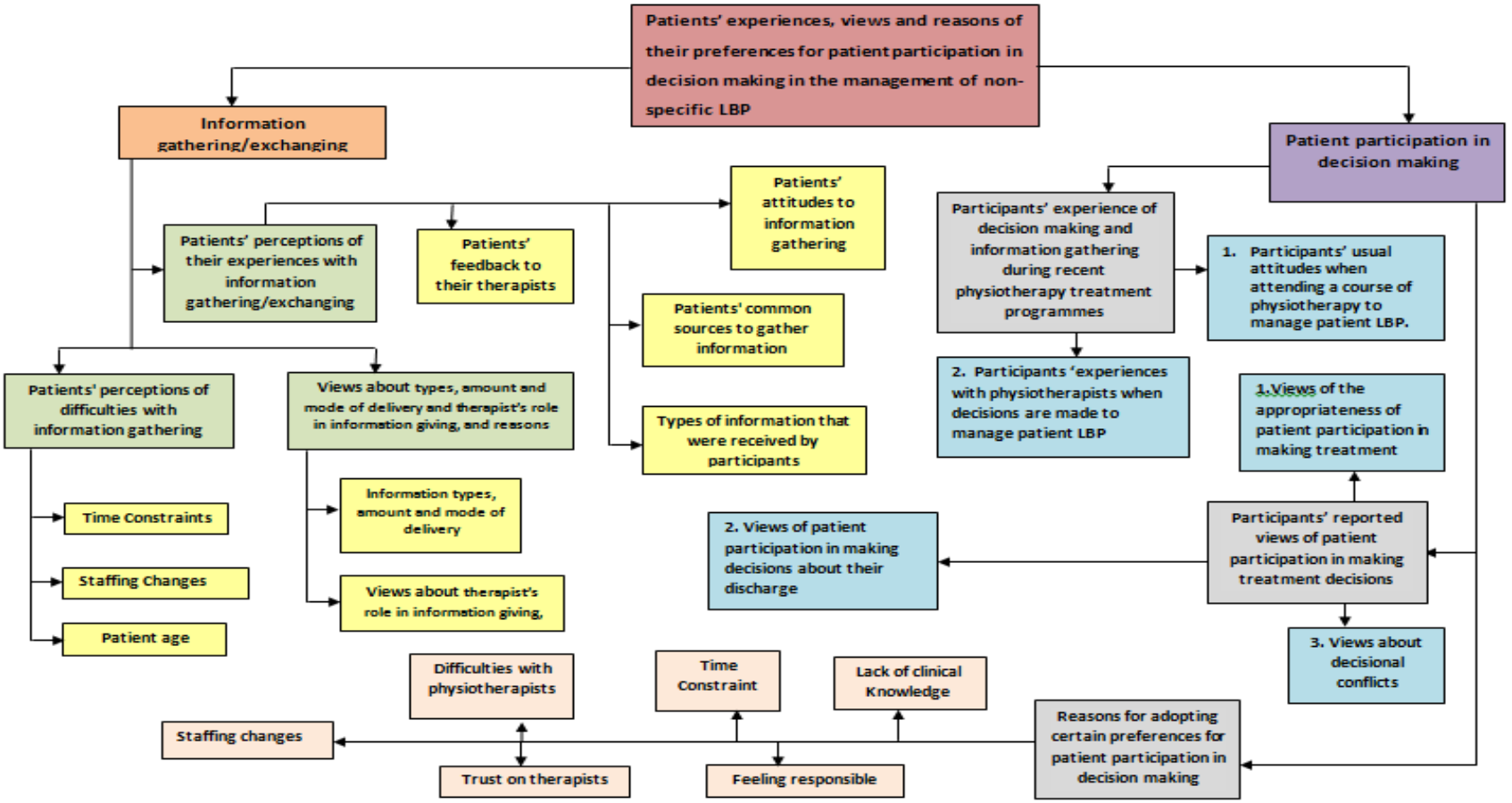

Figure 9.1: Themes and sub-themes representing participants' experiences of physiotherapy for non-specific LBP, their perceptions of the appropriateness of participation in decision making and information provision, and reasons for these preferences

Key: Green=information gathering (IG) themes; yellow=IG sub-themes; light violet=decision making (DM) themes; blue and pink=DM sub-themes

9.5.2.1 Participants' experiences of decision making during physiotherapy for non-specific LBP, their perceptions of the appropriateness of participation in decision making and reasons for these preferences

Three themes and five sub-themes were identified regarding participating patients' experiences and reasons for their preferences for participation in decision making in the management of non-specific LBP. Each theme is referred to as a patient decision making theme (Pt-DM-theme) or sub-theme (Pt-DM-sub-theme). Table 9.4 presents the themes identified with definitions, in relation to the aims of the current study. The quotes are presented with reference to their sources; for example, pt m = male patient; FG6 = focus group 6; 344 = transcript line number.

Table 9.4: Identified themes and sub-themes of participants' experiences of decision making during physiotherapy for non-specific LBP, their perceptions of the appropriateness of participation in decision making and reasons for these preferences

Themes/sub-themes	Definitions	Aims of the focus group study
Theme 1: experiences of decision making **Sub-theme 1/1:** perceptions of what participants do when attending a course of physiotherapy **Sub-theme 2/1:** experiences with physiotherapists when decisions are made to manage LBP	Participants' reported perceptions of their experiences of decision making during recent physiotherapy treatment programmes, including their perceptions of: 1. What patients usually do when attending a course of physiotherapy to manage LBP 2. Their experiences with physiotherapists when decisions are made to manage their LBP	Examining participants' experience of decision making during recent physiotherapy treatment programmes
Theme 2: patient participation in making treatment decisions **Sub-theme 1/2:** appropriateness of patient participation in making treatment decisions **Sub-theme 2/2:** making decisions about patient discharge from physiotherapy service **Sub-theme 3/2:** views about when decisional conflicts arise	Participants' reported views of patient participation in making treatment decisions, including their reported views on: 1. The appropriateness of patient participation in making treatment decisions, including providing patients with treatment options. 2. Patient participation in making decisions about their discharge from physiotherapy service. 3. Views about when decisional conflicts arise between patients and physiotherapists	Examining participants' views of patient participation in making treatment decisions, including its appropriateness, providing patient with options on treatment and discharge, and when decisional conflicts arise
Theme 3: reasons for adopting certain preferences for patient participation in decision making	Participants' reported reasons for adopting certain preferences for patient participation in decision making	Examining participants' views about reasons for adopting certain preferences for patient participation in decision making

1. **Pt-DM-theme 1: Participants' reported experiences of physiotherapy decision making**

This involved examining participants' experiences of decision making during recent physiotherapy treatment programmes. Two sub-themes were identified:

1. Participants' reported perceptions of what they usually did when attending a course of physiotherapy to manage their LBP.
2. Participants' reported experiences with their physiotherapists when decisions were made to manage their LBP.

- **Pt-DM-sub-theme 1: Participants' reported experiences of what they usually did when attending physiotherapy settings**

This sub-theme was discussed by four focus groups. It involved examining participants' reported perceptions of what they usually did when attending a course of physiotherapy to manage their LBP. Participants stated that they usually explained what the problem was in the best way they could and that they then did what the physiotherapist told them to do, without questioning it. In addition, most participants reported that they were unaware of the possibility of treatment options; however, one participant reported enquiring about options for exercises.

> "I just go to get my session and then leave." **Pt f – FG4/157**
>
> "I went to a room two metres by two metres and saw no other options in front of me." **Pt m - FG6/344**
>
> "If he gives me a treatment, whether it is an exercise or anything else, I will do it. I don't have a problem with that." **Pt m - FG5/444**

Pt-DM-sub-theme 2: Participants' reported experiences of physiotherapists making treatment decisions

This sub-theme was discussed by six focus groups. This involved examining participants' reported experiences of being with their physiotherapists when decisions were made to manage their LBP. When asked whether they were offered treatment options, the majority of participants replied that they had been given no treatment options. They were given exercises to do and were told when to come back for treatment. If they requested more frequent sessions, they felt they were ignored.

They described the experience as having been given instructions, rather than options. Several participants were told that some options were unavailable to them. Others reported that some options they suggested were refused by the physiotherapist without explanation.

> "I told them here once that I would like to get more sessions and more machines. She said to me 'Who asked you to decide? We are the ones who decide'." **Pt f - FG3/114**

However, a number of participants had experienced making joint decisions in terms of setting out the plan of treatment. This involved deciding on timeframes and the suitability of the treatment.

> "We put the plan together but my pain disappeared before I finished my sessions! However, even though my pain had gone, we decided to finish the full course of sessions." **Pt m - FG5/597**

A number of participants had some dialogue with the physiotherapist and several felt that their feedback had contributed to decisions made about their treatment. They also appreciated being able to discuss their feedback about the effectiveness, suitability and discomfort of the exercises given by the physiotherapists.

> "I would ask whether I have other options of exercises and whether that machine suits me or not, or whether its power is OK or not." **Pt m - FG6/139**

Pt-DM-theme 2:

This involved examining participants' views about their preferences for participation in decision making. Three sub-themes were identified:

1. The appropriateness of patient participation in decision making.
2. Patient participation in making decisions about their discharge from physiotherapy service.
3. When decisional conflicts arise between patients and physiotherapists.

Pt-DM-sub-theme 1: Participants' views about the appropriateness of patient participation in decision making

This sub-theme was examined by six focus groups. It involved examining participants' views of the appropriateness of patient participation in making treatment decisions, including providing patients with treatment options. Most participants expressed the view that they preferred to rely on their physiotherapists, explaining that this was because they believed that the therapist had the knowledge and the clinical experience required. They noted that the physiotherapists had studied back pain and other types of medical condition professionally. They stated that even if options were provided to them, they would still prefer to be given advice and to follow their physiotherapists' preferred treatment choices. Patients reported that they perceived the relief of pain resulting from their back condition and returning to their normal mobility as more important than participation in decision making.

> "We prefer to leave the choice to the physiotherapist." **Pt f- FG4/204**
> "He will decide and give me what I need." **Pt m - FG7/320**
> "I prefer him to make the decision." **Pt m - FG6/273**

Participants also reported that reaching a correct diagnosis for their LBP problems was more important for them than choosing a treatment, which was the responsibility of the physiotherapist.

> "The most important aspect for the clinician is to be able to diagnose a case. This the most important point, whether the treatment comes from the physiotherapist or myself." **Pt m - FG5/297**

However, others stated that they would be interested in being involved in making decisions about treatment options if the physiotherapists were interested in involving patients and if participation was more beneficial in terms of speed of recovery, matching their exercise preference or exercise suitability.

> "It's good, if the physiotherapist has better things to offer that will be beneficial to me and speed up my treatment, I would want that." **Pt f - FG1/33**
> "This is a good idea that could benefit me and him as well." **Pt m - FG6/49**

Two participants from different groups stated that they might ultimately make the treatment choice.

> "I would say ultimately it is the patients' decision." **Pt m - FG5/682**
> "If I have tried all possible treatments, then I will choose." **Pt m - FG7/113**

The positive views expressed about having choices in treatment decisions were associated with two points that were mentioned by participants:

a. **The suitability of the exercises:** This was linked to the perceived benefits and suitability of the exercises and to the practicality of performing the exercises in a variety of situations and positions.
b. **The level of participant tolerance:** According to the participants, when patients are given treatment options, they may be able to manage their pain as they progress in performing their exercises as part of the recovery process.

> "I prefer patients to be given treatment options so they can choose what suits them out of those options. So I would say this option is good for me and I would like to continue my treatment with it. This would be easier." **Pt m - FG6/231-215**

> "He is the one who should decide from the beginning, but there are certain exercises that make me better and there are others that increase my pain." **Pt m - FG7/218**

Pt-DM-sub-theme 2: Participants' views of their participation in making decisions about their discharge from physiotherapy services

This sub-theme was discussed by four focus groups. It involved examining participants' views of patient participation in making decisions about their discharge from physiotherapy service. Participants reported that the physiotherapists alone made the decision about terminating their physiotherapy sessions. Most participants did not consider that they should have any control over the number of sessions.

> "The physiotherapist decides if I will stop or continue." **Pt f - FG1/123**
> "Usually they give certain numbers of sessions and then say 'This is your last session'." **Pt-m - FG7/242**

In response to a question about when a patient might ask for a discharge from physiotherapy, one participant asserted that this should happen when they felt an improvement.

> "If I feel I'm better, I will say that to him. I will say: 'I would like to end my sessions because I am better'." **Pt m - FG7/267**

In addition, patients indicated that it was not straightforward to request continuation of the treatment; they thought that their physician might be involved in making this decision. The participants did not know the criteria employed by the therapists for a referral for the continuation of treatment beyond the treatment plan.

> "We come here on certain days and we don't know when our treatment sessions will be ended. I mean, every time I come I expect it to be the last time." **Pt m - FG7/281**

Pt-DM-sub-theme 3: Participants' views of occasions when decisional conflicts arise between patients and physiotherapists

This sub-theme was discussed by four focus groups. It involved examining participants' views of occasions when decisional conflicts or disagreements would arise between patients and physiotherapists in the management of non-specific LBP within physiotherapy encounters.

Most participants stated that they preferred to continue a treatment even if it was painful, they did not like it or little progress was made, because they trusted their physiotherapists' professional expertise and the decisions they made. They said that they would follow the advice even if they were entirely unconvinced.

> "Even if I didn't like it, I would do it." **Pt f – FG4/280**
>
> "Whether I like it or not, I would force myself to come for treatment, because I'm in pain." **Pt f – FG4/279**

Participants generally expressed a reluctance to complain about a particular physiotherapist or to request a different therapist when a disagreement arose or when they achieved no improvement. Rather, they expressed a preference to change hospital. This reluctance to complain about an individual was reported by participants to be culturally motivated.

> "It is difficult, one in a million could do it, our society does not accept it, I know." **Pt f – FG4 /783**

A number of participants reported that if they did not agree with the physiotherapist, they would refuse the treatment, seek another opinion or conduct their own enquiries to learn about the proper management. They would use the internet or ask other professionals.

> "I would go for a third opinion. If our opinions do not match, I would like to look for a third opinion to see who has the right one. I would search the internet or ask. He might be right, but I would do some research." **Pt m - FG6/295**

Several participants clearly wished for a negotiation or a dialogue with the physiotherapist. They stated that they would request a more comfortable treatment option or ask for explanations about pain and mobility. They also expressed a desire to discuss the overall management of their condition.

> "If I had previous experience, then I would tell her about it. I would tell her what happened to me, but I would be cautious about her reaction. She might ignore me if I'm telling her about better experiences." **Pt f – FG4/831**

However, some participants preferred to leave the ultimate decision to their physiotherapists, even if they did not agree with it. They considered the physiotherapists' knowledge and professional expertise to be what they came to the hospital for.

"I would like to get the treatment he decides on. I cannot evaluate his work." **Pt m - FG7/297**

"I do have an opinion, but it might be wrong, and she would tell me it's wrong." **Pt f - FG7/821**

Some of the participants pointed out that they might adapt the treatment occasionally if the exercises were painful or difficult to do, or compromise with their physiotherapists. They admitted that they reduced the frequency of exercises or duration, but they still tried to remain committed to the physiotherapist's plan of treatment.

"There should be a sort of compromise between the patient and therapist. It is a psychological compromise as well as the treatment itself." **Pt f - FG4/594**

Pt-DM-theme 3: Participants' reported reasons for not participating in decision making

This theme was discussed by all seven focus groups. It involved participants reporting their perceptions of reasons for not participating in decision making. The following six reasons were raised and discussed by participants.

1. **Lack of clinical knowledge**

Patients assessed their own level of clinical knowledge as insufficient to enable them to make clinical decisions to manage their LBP. Therefore, they suggested that it would be better for their recovery to leave decisions about treatment options to be made by physiotherapists.

"But regarding the choice, I see the physiotherapist as better able to make the decision because he knows better what is good for my condition and he could tell me about the causes of my back pain and the machine he uses or the sessions he gives me."
Pt f - FG6/263

2. Communication difficulties with physiotherapists

Eleven patients reported that the level of communication between them and physiotherapists was reduced by a language barrier (as therapists might speak a language other than Arabic) or because of their perceptions of physiotherapists as uncooperative or not willing to listen to them. This, according to these participants, discouraged dialogue during physiotherapy visits.

> "It depends on the physiotherapists' personality. Some of them smile at you and show you that they are ready to chat with you about the treatment, so you become optimistic that you will recover, but some of them meet you with a gloomy face, then you would rather avoid talking with them." **Pt f – FG6/275**

3. Trust in the physiotherapist

Six of the participants preferred not to participate in making treatment decisions, as they trusted their physiotherapists' knowledge and clinical skills.

> "I trust this place and the people working in it and I trust their opinions." **Pt f-FG1/211**
>
> "I came to this hospital to get treatment and if I already knew the treatment I wouldn't have come here. I came to see people who I believe in and that are qualified" **Pt m - FG5/157**

4. Time constraints

Another six participants thought that the time available for their physiotherapy visits was often limited; therefore they showed their empathy and understanding of physiotherapists being fully occupied with finishing the required treatment, so that they would not have enough time to share treatment responsibilities with their patients.

> **"**He is constrained by time. I don't think he has enough time to speak to everyone. He barely has time to listen to your complaint. He focuses on that and then does his work." **Pt m - FG6/397**

5. Feeling Responsible

Although some participants disagreed, one patient suggested that patients might prefer the physiotherapists to be responsible for them due to having the knowledge and the experience. He thought that if a patient was asked to make a decision, even having been given all of the information, he would ultimately be more convinced by what the physiotherapist had to say, rather than relying on himself.

> "For the sheer responsibility! A patient would prefer the physiotherapist to be responsible for them due to having the knowledge and the experience." **Pt m - FG5/127**

6. Staffing changes

Finally, a few participants (n=5) thought that changing physiotherapists over time would make it difficult for them to participate in making treatment decisions.

> "I'd prefer to have one therapist. That would be better. It would be possible to change the therapist if I got someone better, but if I was going to get someone who had less knowledge and skills, then no, I would never change my therapist." **Pt f - FG3/233**

9.5.2.2 Participants' views about the types and amount of information they wanted to receive, the mode of delivery, difficulties with gathering information, and reasons for their preferences

The chart of the themes and subthemes identified in relation to the information provision domain, resulting from framework analysis, was presented earlier in this chapter, in Figure 10.1 (page 327). This framework analysis of participants' narratives identified three main themes and four sub-themes related to participants' views of experiences and reasons for their preferences for information provision/exchange in the management of non-specific LBP. Each theme was referred to as a 'patient-information theme' (Pt-info-theme). Table 9.5 lists these themes and sub-themes with definitions, in relation to the aims of the current focus groups.

Table 9.5: Themes and sub-themes identified from participants' views about types and amount of information relating to LBP management, mode of delivery, difficulties in gathering it, and reasons for their preferences

Themes/sub-themes	Definition	Aims of the current focus group study
Theme 1: experiences of information gathering/exchange	Participants' reporting of their experience of information gathering/exchange during recent physiotherapy treatment programmes, including: 1. Participants' reported perceptions of their general experience of information gathering. 2. The reported types of information that were received by participants. 3. Participants' reported common sources of information gathered 4. Participants' reported feedback to their physiotherapists	Examining participants' experience of information gathering/exchange during recent physiotherapy treatment programmes
Sub-theme 1/1: general experiences of information gathering		
Sub-theme 2/1: types of information received by participants		
Sub-theme 3/1: common sources of information		
Sub-theme 4/1: patients**'** feedback to physiotherapists		
Theme 2: Types and amount of information that participants wanted to gather and mode of delivery	Participants' views about: types and amount of information participants that they wanted relating to the management of their LBP, mode of delivery (including physiotherapist's role in information giving), and reasons for these preferences.	Examining participants' views about types and amount of information they wanted to gather and modes of delivery, including their perceptions of physiotherapists' role in information giving and reasons for these preferences
Sub-theme 1/2: types, amount and modes of delivery of information that patients wanted to gather relating to the management of their LBP		
Sub-theme 2/2: views of physiotherapists' role in information giving		
Theme 3: difficulties with information gathering	Participants' reported perceptions of difficulties with information gathering	Examining participants' perceptions of difficulties with information gathering/receiving

Pt-info-theme 1: Participants' reported experiences of information gathering/ exchange

This involved examining participants' experiences of information gathering/ exchange with physiotherapists during recent physiotherapy treatment programmes for non-specific LBP. Four sub-themes were identified:

1. Participants' general experiences of information gathering.
2. Reported types of information received by participants.
3. Participants' reported common sources of the information gathered.
4. Participants' reported feedback to their physiotherapists.

Pt-info-sub-theme 1/1: Participants' general experiences of information gathering

This was discussed by five focus groups. It involved examining participants' perceptions of their general experiences of information gathering during recent physiotherapy treatment programmes for non-specific LBP. Most participants reported that they did not ask for or were not given information or explanations by the physiotherapists. Some of them were given treatment instructions, but these were not discussed. The treatment goals were mentioned, but not always explained. It was also reported that instructions were given only at the first session. Other participants stated that they sometimes requested information or explanations about their condition and possible treatment options from their physiotherapists. However, some of them reported negative experiences with gathering information and did not ask for information. This was justified by the need to get rid of their pain, their focus on the treatment rather than gathering information and their negative perceptions of physiotherapists' attitudes, as participants believed that they would not allow them to ask for more information.

Most participants reported that they were sometimes given some information, but not necessarily with enough explanation. They reported that receiving information might depend on the personality of the physiotherapist they were dealing with. If the physiotherapist did not make the patient feel comfortable, then the patient would not feel that it was safe to ask. Participants also reported that they might be given instructions in order to avoid back pain, but which actually increased the back pain. They described being warned that not following up with physiotherapy would result in disability. When instructions were given for the exercises, no advice was given on

how a change of lifestyle could assist recovery and help with prevention of the reoccurrence of their back problem.

> "Sometimes if you ask them they will respond to you. Sometimes you have to see what kind of a physiotherapist you are dealing with. If you feel comfortable, you start to chat and start asking, but only if you feel that he allows you." **Pt f - FG4/488**

Being given information at the same time as instructions was perceived by participants to be beneficial, because they felt it was very encouraging. Participants felt that when they were given no information, they were 'blind' to the treatment process: they did not know how it would progress or what they should expect. One participant stated that he kept asking about his condition because it was his problem and it concerned him.

> "I've found that even if I do the exercises the wrong way, nobody tells me." **Pt f - FG3/79**
>
> "New therapists usually want to get information and chat with you and that makes you more comfortable." **pt-m-FG5/63**

Pt-info-sub-theme 2/1: Types of information received by participants

This sub-theme was discussed by seven focus groups. It involved the types of information that participants reported having received. Patients stated that they were given instructions about posture and movement as well as about the exercises. They were advised about their movements and posture and what movements they should avoid. They were able to discuss information on the equipment used and their workplace conditions. Some participants felt that these instructions helped to explain the nature of their problem and the accumulations of factors that had made the pain more severe, in addition to the benefit of the exercises themselves. Most patients said that they had received verbal explanations, but some instructions were given in the form of brochures and spine models. One participant reported being invited to a

lecture given by a physiotherapist. Another was told at the beginning about the duration of the physiotherapy treatment plan.

> "The physiotherapist explained to me how to get up and sit and discussed my work with me." **Pt f - FG1/254**
>
> "I was given verbal information and they gave me a sheet of paper containing all of the instructions." **Pt f - FG2/52**

Pt-info-sub-theme 3/1: Common sources of information

This sub-theme was discussed by six focus groups. It involved examining participants' perceptions of common sources from which they could gather information, other than physiotherapists. One participant thought that receiving information from the physiotherapist should not stop them from searching for information from other sources.

> "Of course from the physiotherapist; he could direct me through it, but this does not stop me from looking for other sources." **Pt m - FG6/515**

Other alternative sources mentioned by participants included the following: asking another physiotherapist for an opinion; previous experiences of relatives and friends, although this acquired information was not necessarily shared with the physiotherapist; the use of the internet for research about their condition and treatment, which, however, often generated information which they found confusing; educational activities organised within physiotherapy departments; and the personal efforts of treating physicians and participants. Interestingly, participants also stated that they would not challenge the physiotherapist with information gathered from other sources, as they considered the therapist to have the expertise and this was why they had come to the hospital: for the best treatment.

"From neighbours or friends. I would ask her to tell me about the source. She would tell me this exercise is from a physiotherapist or a physician who told her to do it. If she does not tell me about the source, I would not accept it." **Pt f - FG4/300**

"I used the internet. But there weren't many explanations." **Pt f - FG1/54**

Pt-info-sub-theme 3/1: Participants' feedback to their physiotherapists

This sub-theme, which was discussed by four groups, concerned participants' feedback to their physiotherapists on the treatment they had received during recent physiotherapy programmes for their LBP. Patients reported that they gave feedback to the physiotherapist about problems they had experienced with the exercises and about the results of the treatment. They would also tell the physiotherapist if there had been no change, leading them to express concern about the effectiveness of the treatment. One participant stated that it was important to be able to comment on the treatment. Others reported a desire to discuss their condition and to give feedback to the physiotherapist; they felt that it was important to discuss everything, in case the physiotherapist had forgotten something. This was not only about pain; it included the nature of their work, their weight, expectations, previous treatment history, lifestyle and mobility.

"I discussed it with him and told him that I was expecting other things rather than machines." **Pt f - FG2/183**

"I would ask... for instance I would say, 'The treatment you gave me had no result, what should I do?' I have to show my concern." **Pt f - FG4/700**

Pt-info-theme 2: Information that participants wanted to gather and mode of delivery, including physiotherapists' role

This involved two sub-themes:

1. Types, amount and mode of delivery of information that participants wanted to gather.

2. Participants' views of physiotherapists' role in information giving.

Pt-info-sub-theme 1/2: Types, amount and mode of delivery of information that participants wanted to gather

This sub-theme, discussed by five focus groups, concerned the types and amount of information that participants wanted to gather and the mode of delivery of that information. Participants reported that they wanted to know the diagnosis, what the problem was, differences between alternative methods of treating their LBP and what the best treatment would be. They also wanted to have guidance, to be more educated about their condition, to have the underlying reasons for pain explained, to receive more supervision in order to address these reasons and to know if the exercises were being done correctly. Patients wanted the physiotherapist to explain how to adopt a better posture, to listen to patients regarding their feelings and capabilities, to share and discuss the treatment plan and to advise about sleep disturbance. Other reasons for desiring information that were mentioned by participants involved their own interests. Some participants were keen to have more education on LBP prevention. They wanted advice on lifestyle, bad habits and how changes could prevent problems in the future. They wanted to know about precautions and expectations in the future, including things that might happen suddenly, so that they could manage them.

Participants reported that they would benefit from more knowledge about the treatment plan and why certain procedures had been selected. They also wanted clarification as to why sometimes hot was used and sometimes cold, why certain machines were used for some conditions and others not. One patient wished to know the difference between chiropractic and physiotherapeutic treatment plans.

> "No, more for my own interest, I don't like to choose, they must know better"
>
> **Pt f - FG4/207**
>
> "I ask the therapist, which is the best for me? And which would give the best results?" **Pt f - FG4/197**

Participants suggested several ways to deliver information to patients, such as discussions, meetings, lectures and educational films. They also wanted ways of checking if they were doing the exercises correctly. Some stated that they wanted more brochures and charts to be available and suggested that the brochures could have pictures in them. It was generally thought that these brochures should be much more accessible and routinely available in waiting rooms. Charts were recommended by some participants to help them remember the exercises when at home.

> "I wanted to find a brochure about my back pain; there are no brochures in the waiting area." **Pt m - FG6/405**
>
> "Because this would facilitate my communication with the therapist; it would shorten the time because he wouldn't need to spend a long time convincing me or others." **Pt m - FG6/440**

Pt-info-sub-theme 2/2: Participants' perception of physiotherapists' role in information giving

This sub-theme, discussed by five focus groups, involved participants' perceptions of physiotherapists' role in information giving, informed by their recent course of physiotherapy for their non-specific LBP. Many participants expressed the opinion that the physiotherapist should give explanations about the treatment and what to expect. They did not want to just receive the treatment; they wanted information about the treatment plan and advice.

> "I think that therapists should be aware of this and share information." **Pt m - FG5/695**
>
> "They shouldn't just give us the treatment; first they should sit with us and explain what we have." **Pt f - FG4/94**

Participants commented that the physiotherapist should always begin the treatment gradually, with a conversation to explain the reasons for the condition and advise them about what to avoid. It was suggested that talking at the beginning would be better, as the patient would be more likely to be ready to receive information and

less likely to forget things. It was also suggested that this early discussion could take the form of a lecture or tutorial.

> "When we come for the session, it should be more discussion and explanation, like a lecture or tutorial – this would be good." **Pt f - FG4/850**

Participants saw the role of conversation in physiotherapy treatment sessions as important and felt that good communication needed to be established between patient and physiotherapist. They also thought that if a patient feels comfortable and able to talk then more information is revealed. Some mentioned the importance of the feeling of being cared for and reflected that comfortable communication can help when dealing with certain embarrassing situations.

> "Maybe if she chatted with the patient she would tell them more." **Pt f - FG4/411**
> "When she understands what is inside you, you feel comfortable. She asks more and chats with you." **Pt f - FG4/419**

Patients stated that they did not need too much information every time they came for physiotherapy: it was not necessary for the patient to have complete professional knowledge and only pain management advice was necessary. One participant pointed out that too much information can be frightening, while another preferred there to be only a little chat and not every time.

> "He cannot teach me his profession." **Pt m - FG5/58**
>
> "If she initially explained your condition and has given you the exercises, then there is no need to chat to you every time. To me, if she told me everything in the first session, then all that's left to explain is the exercises and I would prefer her to only chat a little." **Pt f - FG4/440**

It was suggested that the production and publishing of the brochures should not be the responsibility of the physiotherapist alone, but that the administration department should sponsor it. In addition, one participant stated the need for the physiotherapist to know about the nature of the patients' work.

"You know, we come here and we don't know anything about what could improve our back pain and what could make it worse. The physiotherapist knows what our problem is and he should give us the brochures about our daily activities that tell us what we should and shouldn't do. I think this should be at the beginning." **Pt m - FG6/444**

Pt-info-theme 3: Participants' perceptions of difficulties with information gathering

This theme examined participants' perceptions of difficulties with information gathering during recent physiotherapy programmes to manage their LBP. The responses are examined here under three headings: time, staffing changes and age.

1. **Time**

Participants in all of the focus groups thought that physiotherapists were always busy and overworked, limiting the time available for them to give information. They felt embarrassed at having to ask for information when they could see that the therapists were working with more than one patient at the same time.

"Maybe embarrassment. Sometimes it's difficult – the therapist may be double booked so time is a problem." **Pt f - FG1/104**

"They don't have time to speak with me or to discuss anything with me. They don't give me any information." **Pt m - FG5/646**

2. **Staffing changes**

Participants in three focus groups thought that it was problematic when physiotherapists changed over time, as types of information and ways to deliver it would also change accordingly.

"My therapist has been changed and when the new one came she was not aware of what I was doing. She asked me what I was doing with the previous therapist and I told her. I still feel like she sometimes forgets what I am doing in terms of the treatment." **Pt f - FG/65**

3. Patient age

A patient in one group thought that despite not asking the physiotherapist for it, he might have been given the information he needed if he had not been so old.

> "I did not ask but they did not give me anything, maybe because of my age."
> **Pt m - FG5/426**

9.6 Discussion

The aim of the current study was to examine in-depth the reasons for participants' views concerning their preferences for patient participation in decision making and information provision, to complement the findings of the cross-sectional survey study (see chapter five). This section discusses its main findings, relates these to the existing literature and highlights a number of clinical implications of the findings. In addition, it undertakes a critical review of the methodological selected and previously justified (chapter 3).

9.6.1 Summary and general discussion of main findings

The results of these focus group discussions confirm the results from the surveys, as present patients receiving physiotherapy treatment for their LBP reported they would like treatment decisions to be either made or largely controlled by physiotherapists. Specifically, patients reported a low preference for active participation in choosing treatment options to manage their LBP, though patients showed a stronger desire to gather clinical information about their LBP condition. The current findings indicate that most participating patients shared a number of reasons not to participate in making decisions or practical barriers to their participation. These reasons can be divided into personal and environmental barriers to participating actively in choosing treatment options.

The first intrinsic reason reported relates to obtaining the best clinical outcome. Patients thought that reducing pain is more important for them and not participating in decision making, thus the great majority of patients with LBP believed that

treatment decisions should be made by physiotherapists, while a few felt that participation in decision making was 'interesting' if it might benefit them by speeding up their recovery, helping to take account of their physical tolerance to exercise and enabling them to provide feedback on the suitability of the prescribed exercise. However, patients also thought that they would be able to participate in making decisions only where these did not require clinical knowledge, believing they would otherwise risk impairing their recovery or worsening their LBP.

Lack of clinical knowledge and experience was highlighted as a reason for not preferring to take part in decision making; participants reported a high level of trust in their physiotherapists. An explanation for this may be participants' perceptions of limited self-competence to manage their illness and their sense of reliance on others to improving their symptoms was a key reason for preferring the therapist to make most decisions. They reported 'not knowing' about LBP, the best treatments or how to approach its management. This lack of confidence to be able to make the best decision may be related to patients' fear of change (taking a new initiative) or low self-efficacy regarding their ability to take an active part in setting treatment plans to manage their LBP. The literature suggests that LBP patients' perceptions of pain experience are complex and can influence their psychological status possibly reducing self-efficacy and increase their fear of movement (Foster et al., 2008, Foster and Delitto, 2011), possibly leading to their preference for treatment decisions to be made or controlled by the therapist. Further explanation on LBP impact to reducing patients' perceptions of their self-abilities to manage their LBP condition is provided in chapter eleven.

Finally, difficulties in clinical communication with their physiotherapists were reported as barriers to implement SDM (Légaré et al., 2008, McIntosh and Shaw, 2003). In addition, The personal skills of physiotherapists in communicating ideas and views, being understanding and listening (Cooper et al., 2008, Slade et al., 2009), may direct the way in which patients and clinicians view or define medical problems during their clinical interactions.

Extrinsic barriers identified and reported by participants included time constraints and variable; treatment plans with the therapist being replaced. Patients wanted to devote the time spent in the clinical setting to receiving the treatment they believe they need prioritised the importance of receiving consistent approaches to their care, preferring it to come from a the same therapist. These two factors become more problematic in private physiotherapy settings. No indications in the reported competencies of SDM appear to address these barriers, and efforts to overcome such barriers remain individual.

Finally, though not identified specifically as a reason by the patients; the model of health care that both therapists and patients experience may be a key factor. Patients' accounts of their experiences when attending for physiotherapy for their LBP confirmed our expectation that, despite some encouragement to adopt a more biopsychosocial model of care by the Saudi government, the biomedical model of healthcare dominates physiotherapy practice and patient expectations in Saudi Arabia. Participants did not perceive the involvement of LBP patients in making physiotherapy treatment decisions to be a common practice in Saudi Arabia. They expressed a traditional perception of the clinician as having the principal role in controlling clinical decisions. Their responses indicate the prevalence of a biomedical model of decision making that gives the responsibility and authority to clinicians to make clinical decisions; thus patients did not expect their opinions regarding treatment choices to be sought.

The present findings indicate that information sharing was perceived by patients as an essential component of the physiotherapeutic management of LBP. Patients reported they were not often invited to ask questions concerning their condition, and that they seldom initiated clinical enquiries about their LBP, because they felt it to be the responsibility of the physiotherapist to provide them with the clinical information they needed without being asked. As patients regarded their physiotherapists as their only reliable and trustworthy source of information, they expected to receive advice and instructions from them to enable them to self-manage their LBP, to alleviate difficulties with daily activities, to avoid further complications and to learn to live with

their LBP. This strong reliance of patients on their physiotherapists as a main source of clinical information may increase demands on time needed for physiotherapy encounters and accordingly may reduce opportunities to identifying enough time to share decisional responsibilities between patients and therapists.

9.6.2 Discussion of main findings in relation to the literature

One point noted above is that patients considered themselves unable to participate because they lacked professional knowledge and experience. This finding is consistent with those of an earlier questionnaire-based study conducted in the United States by Thompson and colleagues (1993), which asked patients (n=459) suffering various health conditions, including cancer and other chronic diseases, about their preferences for involvement in making decisions and reported as here that participants felt able to participate in decisions that did not require clinical expertise. More specifically and recently, lack of clinical knowledge was also reported as a barrier to LBP patients being fully engaged in the planning and deciding on the treatment (Cooper et al., 2008, Slade et al., 2009).

There is evidence of patients' reported views about their involvement in decision making as part of 'patient-centeredness', in self-management and in goal-setting. In the UK, Cooper and associates (2008) elicited the perceptions of patients with LBP of the concept of patient-centeredness and report that patients believed that clinical decisions should again be made by physiotherapists because of their professional expertise. While the current results are in line with this finding, the authors acknowledge that patient-centeredness has other dimensions in addition to participation in decision making (e.g, information provision, individual care and communication) (Cooper et al., 2008). As a model of clinical practice, patient-centeredness is inevitably placed closer to the patients' side, considering them as the core of the healthcare process, while the SDM model of patient involvement in decision making often supports a more balanced interaction between clinicians and patients, encouraging both of them to establish common ground on the making of treatment decisions.

Other studies have reported more mixed results with a desire for sharing DM being most prominent. The present finding that patients preferred a more passive decisional role is in contrast with a qualitative study, conducted in Australia by Slade and colleagues (2009), who elicited the views of patients with chronic LBP (n=18) about their experiences of participation in and engagement with exercise regimes. Although this study was not conducted within a physiotherapy context, it is of interest here that patients reported a desire to negotiate treatment plans and to work in partnership with their healthcare providers; they wanted to be fully engaged with the health professionals and to feel that their views concerning treatment were well recognized. Health care models and cultural expectations and behaviour (discussed further in chapter 11) differ greatly between Saudi Arabia and Australia and this may to some degree account for the difference. When Payton and colleagues (1998) examined the views of patients in rehabilitation settings (n=109) on their roles in decision making and their relationships with health professionals, they found that more than half of patients wanted to share in making decisions, although they did not know how to do so.

Experience also seems to play a role in preferences. In Australia, Grimmer and colleagues (1999) noticed a difference between novice and expert patients suffering acute LBP: those attending physiotherapy settings for the first time tended to be more passive than those who had received physiotherapy treatment more than once. Perhaps treatment and expectations of treatment outcome contribute to determining the desire of expert patients to be informed and their preferences for participation in decision making. Not all of the patients who participated in the current study were new to physiotherapy setting.

Most of the above mentioned reasons reported by participants for adopting passive roles by patients have previously been identified in other studies with patients with LBP (Cooper et al., 2008, Slade et al., 2009, Verbeek et al., 2004, Dean et al., 2005). For instance, these studies underlined communication as a key element in patients' perceptions as to whether clinical care is customised or individualized to their needs. The current findings suggest that patients with LBP want meaningful communication

with their physiotherapists. Respondents indicated that poor communication might give them the negative impression of being ignored and not being heard or seen by the physiotherapist, which might in turn prevent them from asking questions and stating their needs. They thought that inadequate communication by physiotherapists might increase their uncertainty and worries about their LBP condition. Studies by Cooper et al. (2008) and Verbeek et al. (2004) found that patients with LBP did not to seek an active role during clinical encounters, preferring instead to rely on their clinicians' knowledge and clinical skills. Cooper et al. (2008) report that patients emphasized the importance of effective communication between them and their physiotherapists as a key component of patient-centeredness. The current findings indicate that patients may have been influenced by both verbal and non-verbal communication with their physiotherapists, interpreting some responses as being 'ignored'. This was reported to inhibit patients' desire to engage with their physiotherapists in making decisions. Verbeek and colleagues (2004) report that patients with LBP felt dissatisfied, frustrated and angry when clinical communication was insufficient. Their review concerned the expectations and satisfaction of patients with LBP and concluded that patients with LBP wanted their healthcare professionals to communicate adequately with them and to provide them with accurate clinical advice and information about their LBP condition.

An individualised approach to care was reported as important by four participants, who perceived this to be an effective approach to achieving better outcomes; they also felt that good communication would facilitate this approach. The reasons for this are unclear but may be relate to a strong wish for the most effective care. Patients' demands for the individualization of their treatment were consistent with the above-mentioned studies and with the findings of Payton et al. (1998) and Slade et al. (2009).

Several studies have highlighted the effect of time constraints on the implementation of the SDM model during medical consultations (Légaré et al., 2008, Whitney et al., 2008), and participants in the current study reported that their physiotherapists' professional time was limited, affecting communication. This is unsurprising, as SDM competencies require extensive clinical interaction and presume a good level of

communication. Dean and associates (2005) report a similar finding and suggest that physiotherapists may struggle to communicate adequately with their patients because their time is taken up with performing clinical assessments and delivering treatment.

Participants indicated a preference for a passive role, including in conflict situations. A factor possibly influencing this preference is participants' trust in their health practitioners, as reported in a Canadian study by Kraetschmer and colleagues (2004), who examined the views of patients at three out-patient clinics (breast cancer, prostate cancer and fracture). They suggest a negative relationship between level of trust and preferences for decisional roles: the preference for a passive decisional role was significantly associated with high levels of trust in physicians, whilst a preference for autonomous or active roles was associated with low levels of trust. Our sample reiterated that they 'trusted' their therapists, for many reasons, including therapists' high clinical skills.

Making decisions about patient discharge from physiotherapy services appeared as a distinct theme in the current study. Patients with LBP expressed a strong desire to have a role in deciding on their discharge from physiotherapy services, on the frequency of clinical visits and on follow-up appointments. These findings are in agreement with those of the survey study we also undertook. Other studies have also reported a desire among patients to approach their physiotherapists after being discharged from physiotherapy services. For instance, Cooper and associates (2009) found that patients with LBP felt that they needed to have access to their physiotherapists after discharge from the outpatient clinic. A perceived need to approach physiotherapists after finishing clinical sessions was also observed by Hills and Kitchen (2007) in patients suffering chronic musculoskeletal conditions. While neither of these relate directly to the time of discharge, they indicate a need to have continued access to care, although no reasons are given for this. Cooper et al. (2008) present a similar finding from the United Kingdom; however, patients reported their need to remain able to obtain professional help from their therapists, in case they needed treatment. This suggests low self-confidence among patients with LBP regarding their ability to manage their LBP away from the clinical setting.

Studies with patients with LBP confirm our work that patients' have a stronger desire to receive clinical information than participation in decision making (Cooper et al., 2008, Slade et al., 2009). Other studies, which agree with ours, have suggested that patients become more satisfied when they receive adequate information (Hills and Kitchen, 2007, Payton et al., 1998). The present findings are consistent with those of earlier studies (Deber et al., 1996, Stewart et al., 2004) in indicating that patients' information needs were not necessarily related to their desire to be involved in making decisions about their health care; rather, patients expressed a desire to receive information in order to know what would help them to avoid complications related to LBP and to self-manage their condition. Participants wanted this to be delivered in practical and simple ways that they could easily approach and understand. Results from a systematic review by Lyndal and colleagues (2004) proposed that interventions to enhancing delivering information to patients were found more effective when these are individualized to patients' needs and information is structured. Yet, none of the involved studies provide explanations on how and why improving patients' understanding can encourage patients to make health related decisions despite of the differences in their educational backgrounds. One reason participants wanted information from their therapist was that they did not trust information gathered from other sources and related this to their trust in the professional knowledge; they described the amount of information they tended to receive from their physiotherapists as inadequate. Their criticism of physiotherapists for not reviewing and updating the information given, an approach advocated by Moffett (2002) who suggested that information provided to patients with LBP should be periodically reviewed and updated to suit patients' needs.

9.6.3 Methodological critique

The choice of methodology – focus groups - was guided by a number of factors, most of which are discussed in chapter 3. A key reason for using group work was that using one to one interviews in Saudi Arabia was not possible for mixed gender interactions; this the female interviewer could not interview male patients individually. In addition, previous research work in Saudi Arabia has reported that

limited amounts of data are derived when participants are interviewed individually. Reasons could be varied but are most likely to relate to lack of confidence and concern at giving wrong answers. These reasons supported selecting the focus group study as method to collect in-depth data about potential reasons for whether patients prefer to participate in the decision making process or not, in addition to their perceptions on potential difficulties to their participation. It was also not possible to have patients from both genders in the same focus group, and female and male patients were interviewed separately. While it is unlikely that this affected what was said negatively – and most likely increased participation – it is important to note this difference.

One benefit of the approach was that, in contrast to the survey study, illiterate participants were eligible to participate. A further benefit was that by employing the focus groups, participants were encouraged to express their views as it allowed more group interaction, and further ideas were stimulated to come through the group discussion. While using this method was successful in producing rich data on the research topic, the generalizability of conclusions revealed by this method remains limited.

9.6.4 Implications for practice

The findings of the current study are of importance to physiotherapy practice to manage patients with non-specific LBP and have a number of clinical implications:

- Improving level and quality of communication between clinicians and patients may play a role in facilitating patient participation in decision making.
- Providing patients' with clinical information that addresses patients' needs, seem to a key factor in promoting their perceptions of their abilities to self-manage patients' LBP.
- The current study specifies some examples of information needs of patients with LBP in Saudi Arabia. This can assist with focusing physiotherapy education programs on patients' needs.

- This study supports a shared management plans for LBP in home settings.
- Providing patients with information they want can facilitate more positive interactions during setting treatment plans to manage patient LBP.
- Patients should be initially heard and given opportunities to express their needs and whether they have a preference to participate in making treatment decisions or not.

9.6.5 Conclusion

Patients' perception that they lacked the professional knowledge and clinical skills to participate in decision making, in addition to time constraints during physiotherapy visits appeared to be patients' main reasons for a limited desire for participation in making treatment decisions. However, patients wanted more information that they could use to self-manage their LBP condition and to avoid further complications in the future; this may have been driven by the increasing anxiety level associated with LBP. The results of this study suggest that patients may consider their needs for clinical information to be more important than their actual participation in the management process.

Chapter Ten

Study 5: In-depth examination of physiotherapists' views on patient involvement in the management of non-specific LBP, their perceptions of the appropriateness of patient participation in decision making and information provision and reasons for these preferences

10.1 Introduction

This chapter reports the use of focus groups to investigate physiotherapists' views on patient involvement in the management of non-specific LBP, their perceptions of the appropriateness of patient participation in decision making and information provision and reasons for these preferences. The use of this qualitative method, the selection of study sites and the sampling technique were all justified in chapter three, while the development and testing of the focus group topic guide and the process of analysis of the results were described in chapter eight.

10.2 Aims

This focus group study aimed to elicit, from physiotherapists treating patients with non-specific LBP, details of:

1. their usual practice with respect to decision making and information giving when managing such patients;
2. their preferences and views about patient participation in making treatment decisions;
3. their preferences and views about the types, mode of delivery and amount of information they preferred to provide in relation to the management of LBP and their perceptions of potential difficulties with information giving;
4. their reasons for adopting these preferences.

10.3 Method

10.3.1 Study Design

Three focus groups of physiotherapists treating patients with non-specific LBP (n=18; 5-7 physiotherapists per group) were conducted in December 2010 and January 2011 in Riyadh, using semi-structured interviews with open-ended questions.

10.3.2 Participants

A total sample of 18 female and male physiotherapists who treated patients with non-specific LBP and who worked in the physiotherapy outpatient services of the selected hospitals was selected. See the previous chapter for details on study sites selected.

Selection criteria

Participants were recruited if they had clinical experience in musculoskeletal physiotherapy of at least 2 years and worked in Riyadh city. They also had to be registered at the Saudi Commission for Health Specialists and to manage patients with non-specific LBP as a routine clinical practice, seeing at least three patients per week.

10.3.3 Ethical Approval

See section 9.3.3 in the previous chapter for details on Ethical Approval.

10.3.4 Procedure

10.3.4.1 Recruitment

Details on the recruitment procedure of the study site are provided in section 9.3.4.1 in the previous chapter.

10.3.4.2 Focus group procedure

Three focus group sessions were held, each involving male and female participants. All sessions were conducted in Arabic, but the language was mixed with English when technical terms (e.g. ‘therapeutic approaches’) were used. The focus groups met in

conference rooms which were suitable to ensure the confidentiality of the discussions. Refreshments were provided.

The discussions were guided by the topic guide (see Table 10.1). Further details on focus group procedure are provided in section 9.3.4.2 in the previous chapter.

Table 10.1: Topic guide for physiotherapist focus groups

Opening question (Aims: breaking the ice and engaging participants**)** - In your opinion, to what degree can physiotherapy help patients with LBP? **Transition question (Aims:** introducing the topic and exploring perceived experiences of physiotherapy settings**)** - Do your patients participate with you in making treatment decisions?	
Key areas: Overall views of patient participation in making treatment decisions and giving information	
Domain 1: Patient participation in decision making	
Probes	**Aims related to questions**
1) Perceptions of their usual practice of decision making when managing patients with non-specific LBP	**1**
2) Perceptions of the appropriateness of patient participation in decision making, including potential benefits and shortcomings	**2**
3) Views on patients being provided with treatment options/choices	**2**
6) Perceptions of situations when decisional conflicts arise between patients and physiotherapists	**2**
	2
4) Reasons for adopting certain preferences for patient participation in decision making	**4**
Domain 2: Information provision	
Probes	**Related aims of this domain**
1) Perceptions of previous clinical experience of information giving as part physiotherapy process to manage LBP.	**1**
2) Reasons for adopting certain preferences for giving clinical information about managing patient LBP	**4**
3) Views about the types, amount and mode of delivery in information giving relating to the management of patients' LBP in physiotherapy settings	**3**
4) Difficulties and facilitating factors for giving clinical information about managing LBP	**3**
Closing question: Do you think that applying this type of practice (involving patients in treatment decisions) needs special skills? If so, what are they? **Conclusions and thanks**: Would anyone like to add anything?	

10.4 Data analysis

All the focus groups were transcribed verbatim, translated to English and then back translated to Arabic (chapter three for the translation procedure) were Framework analysis was used to analyse data derived from the focus groups (Ritchie and Spenser 1994). A detailed explanation of this analytical approach is provided in chapter eight. The NVivo software program (version 8) was used to categorize the identified codes, as described in chapter eight.

10.5 Results

This section reports participants' demographic characteristics and the main themes and sub-themes emerging from the focus group discussions.

10.5.1 Demographic characteristics

Of 28 physiotherapists invited, 18 agreed to participate. The number of participants in each group is shown in Table 10.2 and their demographic characteristics are presented in Table 10.3.

Table 10.2: Number of participants per focus group

Group number	Number of participants (n=18)
1	**7**
2	**6**
3	**5**

Table 10.3: Participants' demographic characteristics (n=18)

Demographic	Number of participants (n=18)	Percentage %
Age		
24-30	10	56
31-35	3	17
36-40	2	11
41-45	2	11
> 45	1	6
Gender		
Male	9	50
Female	9	50
Years since graduation		
< 5	7	39
5-7	3	17
8-10	2	11
11-15	2	11
> 15	4	22
Professional qualifications		
Bachelor Degree	13	72
Professional Master	2	11
Professional Doctorate	1	6
Others	2	11
Work position		
Staff Therapist	7	39
Senior Therapist	8	44
Specialist/Clinical Supervisor	3	17
Average new LBP patients/week		
< 3	3	17
3-5	3	17
> 5	12	67

10.5.2 Focus groups findings on participants' views on patient involvement in the management of non-specific LBP, their perceptions of the appropriateness of patient participation in decision making and information provision and reasons for these preferences

The next two subsections report the views expressed by focus group participants. The subsequent framework analysis identified themes and subthemes related to the topic guide, presented in Table 10.4 and Figure 10.1. All identified codes are presented in tables containing the original transcripts of the focus groups, the themes and sub-themes identified and the transcript line numbers. All the transcripts are presented in an attached CD to this thesis.

Table 10.4: Themes and sub-themes reporting participants' views of their usual practice of decision making when managing patients with non-specific LBP, their preferences for and perceptions of the appropriateness of patient participation in decision making and reasons for these preferences

Identified themes/sub-themes	Definitions	Study aims
Theme 1: Perceptions of participants' usual practice when making treatment decisions	Participants' perceptions of their usual practice of decision making when managing patients with non-specific LBP	**1**
Theme 2: Patient participation in making treatment decisions	Participants' preferences and perceptions of the appropriateness of patient participation in decision making when managing patients with non-specific LBP	**2, 3, 4**
Sub-theme 1: Patients' preferences for treatment decisions	Participants' perceptions of patients' having preferences for treatment decisions about managing their LBP	
Sub-theme 2: The concept and appropriateness of patient participation in decision making	Participants' perceptions of the appropriateness of patient participation in decision making when managing patients with non-specific LB	
Sub-theme 3: Providing patients with treatment options	Participants' views about giving treatment options to patients with non-specific LBP as part of their physiotherapy management	
Sub-theme 4: Decisional conflicts	Participants' views about situations when decisional conflicts arise with their patients during physiotherapy to manage non-specific LBP	
Sub-theme 5: Reasons for not involving patients in making treatment decisions	Participants' perceived reasons for their preferences for not involving patients in making treatment decisions	
Theme 3: Alternative approaches to patient participation in decision making	Participants' views on approaches they use or might use as alternatives to patient participation in decision making	**2**

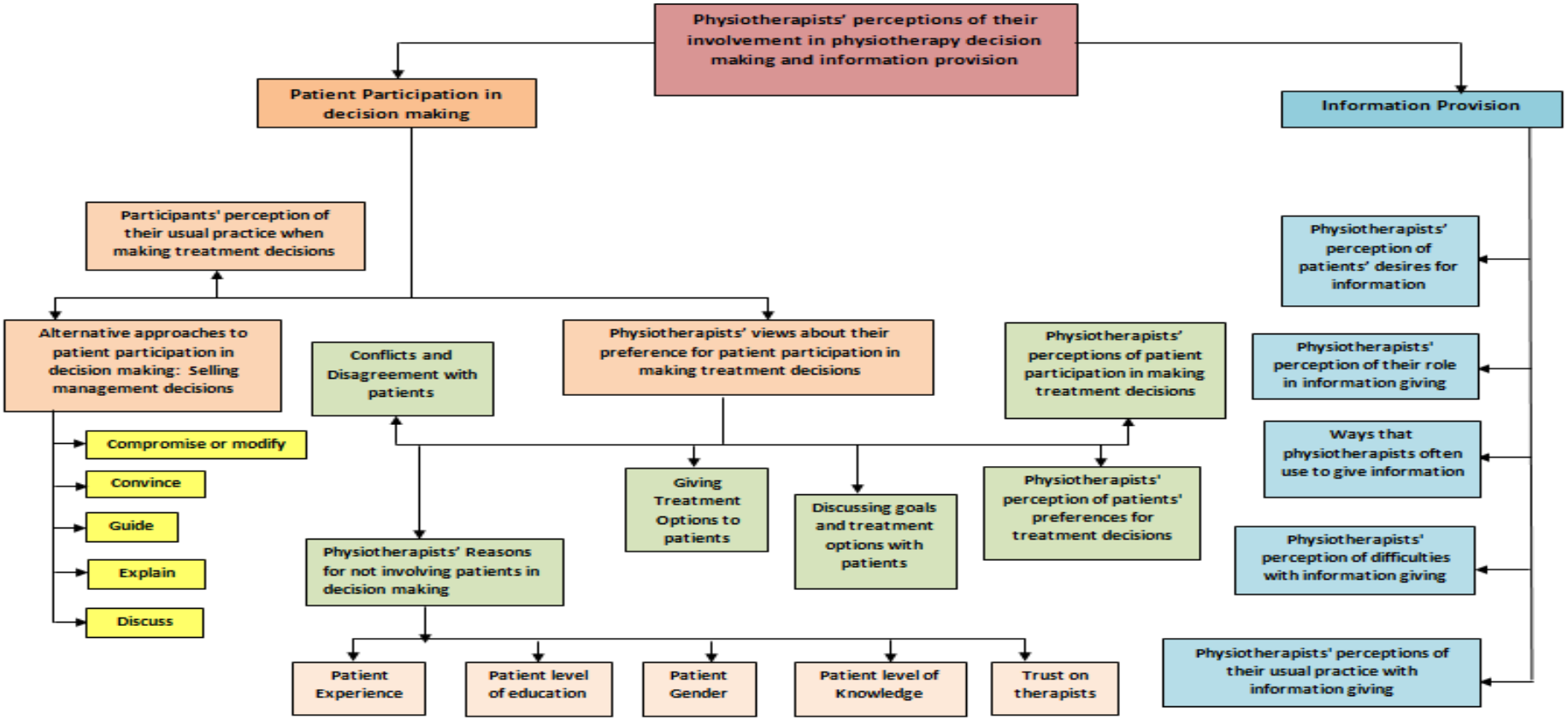

Figure 10.1: Themes and sub-themes representing participants' experiences of physiotherapy for non-specific LBP, their perceptions of the appropriateness of participation in decision making and information provision, and reasons for these preferences

Key: blue: information giving themes, orange: decision making (DM) themes, green and yellow: DM sub-themes

10.5.2.1 Participants' views of their usual practice of decision making when managing patients with non-specific LBP, their preferences and perceptions of the appropriateness of patient participation in decision making and reasons for these preferences

Three themes and five sub-themes emerged concerning participants' experiences and reasons for their preferences for patient participation in decision making in the management of non-specific LBP. Each theme is referred to as a 'physiotherapist decision making theme' (Ph-DM-theme) or sub-theme (Ph-DM-sub-theme). Table 11.4 (page 364) lists the emergent themes with definitions, in relation to the aims of the current focus groups. The quotes presented below are referenced to their source as in the following example: ptm = patient male, FG6 = focus group 6, 344 = transcript line number.

Ph-DM-theme 1: Participants' reported perceptions of their usual practice of decision making when managing patients with non-specific LBP

This theme examined participants' perceptions of their usual practice of decision making when managing patients with non-specific LBP.

Treatment decisions are usually made after a number of subjective and objective examinations. Participants' usual practice was to follow the route of assessment based on objective evidence. Decisions were made and treatment approaches developed as part of the assessment procedure. However, participants acknowledged that they sometimes felt it necessary to ask a patient for a treatment preference, especially where a patient was elderly or had previously had advice from sources other than physiotherapists. Participants also reported that their treatment goals would often involve both therapist and patient. The reported goals included the duration of the treatment, the home exercise plan, use of equipment and invasive procedures. Participants reported that it was their usual practice to reassure patients that the treatment plan was specific to their problem and to the goals identified. One participant stated that it was usually necessary to gain consent for the invasive treatment he used to manage LBP (dry needling).

> "It's best to follow the route that evidence has proven, but sometimes we have to consider the patient's preference, especially the elderly or those who have had advice from others." **Ph-FG2/161**

Ph-DM-theme2: Participants' views and perceptions of the appropriateness of patient participation in decision making

The second theme concerned therapists' views and perceptions of the appropriateness of patient participation in decision making. Five sub-themes were identified:

1. Perceptions of patients' preferences for management decisions.
2. Perceptions of the concept and appropriateness of patient participation in decision making.
3. Views about giving treatment options to their patients.
4. Views about situations when decisional conflicts arise with patients.
5. Perceptions of reasons for not involving patients in making treatment decisions.

Ph-DM-sub-theme 1: Perceptions of patients' preferences for treatment decisions

This sub-theme examined participants' perceptions of patients' preferences for making decisions about managing their LBP. Therapists reported that some patients might listen to their friends' and relatives' accounts of effective and ineffective treatments they had received, then ask for a certain treatment, believing it to be the best one. Participants stated that they commonly found that patients compared their conditions and treatments among themselves. They felt that these comparisons might make it difficult for patients to accept the physiotherapist's assessment and treatment plan, which had been made specifically to suit each patient. Participants thought that patients might want to have specific treatments and would then be resistant when these demands were refused by the physiotherapist.

"Sometimes, she might have heard from her neighbour that she has used electrical vibrations and found it useful or she might have received a previous treatment and had some improvement, so she comes with this dominant idea that guides her." **Ph-FG2/142**

Participants reported that there were some patients who considered that they were knowledgeable and sophisticated and who might "interfere" with the decision making process and try to make treatment decisions on their own. Patients who had received treatment at other centres might sometimes consider themselves to have experience of therapeutic equipment and participants thought that this could cause decisional conflicts with physiotherapists in making treatment decisions. It was also mentioned that some patients appeared not to trust the decisions made by physiotherapists; they would challenge them and be unable to accept them. According to participants, this was especially likely to occur when patients believed the cause of their medical condition to be different from what the physiotherapist suggested.

"We have types of patients who really know what they want; they come to me and say 'please treat my pain' and then they leave." **Ph-FG2/96**

"This is not a real patient who comes and imposes certain treatment on you when he comes and wants a particular thing." **Ph-FG2/196**

Conversely, participants stated that other patients were passive and would accept the treatment. They reported that some patients just wanted pain relief and then to leave. One participant commented that most patients liked hands-on treatment by physiotherapists, regardless of whether they were convinced of the effectiveness of the treatment. Participants were in consensus that patients believed that massage was the best treatment they could have and would thus all request it if they could.

"Some patients come to us very passive and ask what we think is best." **Ph-FG2/166**
"There are some patients who are completely passive, so we do the best for them." **Ph-FG2/170**

Participants thought that the discussion with patients should not aim to share making decisions with them. Rather, they felt that they might use the discussion in order to clarify treatment options for patients.

> **"**Of course, I discuss with the patients, but you know it's not like they can come to me and tell me what I should do for them. Of course they can say what they think. Then I decide and then discuss with them. It's not like they can decide what would be nice. I decide." **Ph-FG3/482**

Ph-DM-sub-theme 2: Participants' perceptions of the concept and appropriateness of patient participation in decision making

This sub-theme examined participants' perceptions of the concept and appropriateness of patient participation in decision making when managing patients with non-specific LBP.

Although the participants reported uncertainty as to how patient participation in decision making should be described, they made a number of suggestions, i.e. that participation might involve the following: complying with the treatment given by the physiotherapist; giving feedback about the plan of treatment; motivation, acceptance and adherence to treatment; and the patient's understanding of the treatment plan. Participants thought that participation was positive when patients were committed to what physiotherapists suggested and vice versa. They also thought that patient participation could be implemented by encouraging patients to talk about problems caused by their back pain and to give a history as part of the assessment; they should also be asked to give feedback on the treatment.

> "By following the instructions, he can give me feedback in the sessions on which were more effective for him." **Ph-FG1/144**
>
> "A patient could participate in the treatment by following the therapist's advice." **Ph-FG1/66**
>
> "I will accept his feedback and see this as him participating in my treatment." **Ph-FG3/562**

Participants felt that patient participation could occur by encouraging the patient to comply with the therapist's instructions, to do certain things and to avoid doing other things, then the physiotherapist could explain why certain procedures could be done and why some could not be carried out.

Participants felt that patient participation in decision making was a negative contribution to physiotherapy and should be minimal. They suggested that the following levels of participation should be considered: patients benefiting from the discussion and being informed about the modalities; or benefiting from being educated about their condition, including knowing the source of the problem, the reasons for pain and the likely outcome of the treatment. However, participants suggested that it would assist patient participation if physiotherapists had special training in educating patients from different social and educational backgrounds; hence, involving patients in decision making would require creativity and perception as well as the training itself, in order to support the physiotherapists.

> "Especially the issue of participation; this is not applicable for physiotherapy." **Ph-FG2/796**
>
> There should be level of participation but not to the level that they choose the treatment. This level can depend on different situations" **Ph-FG3/491**

Participants pointed out that setting treatment goals with patients could be considered as participation, since patients were able to give their opinions.

> **"**The patient and I might want to reach our goal in a short space of time, so there has to be participation to reach this goal." **Ph-FG3/557**

Ph-DM-sub-theme 3: Participants' views on giving treatment options to patients

This sub-theme concerns participants' views on giving treatment options to patients with non-specific LBP as part of their physiotherapy management. There was general consensus among participants that it was for physiotherapists, not patients, to choose, because they had the experience and knowledge to make clinical decisions.

Thus, a number of participants considered that patients should not be given any options. They suggested that some patients would not benefit from awareness of options. Other participants suggested keeping the options limited. They thought that patients needed to be aware that not many options were available in the department and that not all options were appropriate to each condition. However, a few participants thought that it might be appropriate for patients to choose from a range of options, but not to choose the options; patients could end up doing nothing if they were given options. Participants felt that giving too many options could be confusing for some patients. It was not optional for patients to do the exercises or not; rather, they thought that patients should participate through adhering to the treatment and applying the instructions. In the case of a patient insisting on a particular procedure, participants considered this inappropriate.

> "Give them options about their treatment? Um … No, not too many options, because there are not many options available. I will suggest what I really want to do and then I would advise that this will be the treatment." **Ph-FG3/55**
>
> "I don't believe that treatment options can be shared with patients." **Ph-FG2/318**

Participants thought that encouraging patients to participate in making decisions about treatment options could be considered appropriate only if the treatment outcome would be the same with all interventions or where the physiotherapist was uncertain about the outcome. According to participants, an appropriate treatment choice would be whether to do an exercise at home or at work; they thought that this level of choice could make the patient more positive. Another example would be for patients to be invited to choose between hot and cold packs, or to decide whether to accept the physiotherapist's recommendation to buy a device like the TENS to use at home. They also thought that offering patients a treatment choice might be considered appropriate on occasions such as when an invasive procedure was recommended by the physiotherapist.

"I may give him a choice between two treatment options if I am not sure myself which one is better. I give him two exercises and see what suits him." **Ph-FG2/88**

"The patient may also participate in choosing one exercise over another, of two that I may have already tested out with him. So this participation is apparent, but still limited." **Ph-FG3/193**

Ph-DM-sub-theme 4: Participants' views about situations when decisional conflicts arise with their patients

This sub-theme examined participants' views about situations when decisional conflicts arose with their patients during physiotherapy to manage LBP. Participants stated that coming into conflict with patients was inappropriate and that treatment should be agreed between therapist and patient. It was generally regarded as wrong to force a patient or to impose a certain type of treatment and equally unacceptable for patients to impose a choice.

"We are here every day to find the solutions to our patients' problems and find an agreement between the patient and ourselves. It is not a fight! We are here for the patients." **Ph-FG2/438**

"I cannot force a patient to receive a certain treatment. We cannot force people to do something they don't want to do." **Ph-FG2/598**

However, the possibility of not accepting what patients wanted or suggested as a preference for treatment was raised by participants, who suggested a number of ways to avoid conflicts with patients. The first was using persuasion to convince a patient, as they thought that some patients might need encouragement to follow a treatment plan, having had a bad experience in the past. Alternatively, if the patient insisted on a treatment which the physiotherapist considered inappropriate, then the therapist could say that the necessary equipment was not available. Finally, a physiotherapist might try to gradually wean a patient off disputed treatment sessions.

> "I wouldn't change my mind. If he thinks that what I am suggesting is wrong and he doesn't feel comfortable in my hands, I would just have to let him know that I know best and he needs to trust me, otherwise he can go back to my supervisor and change therapist." **Ph-FG1/233**

One of the more difficult clinical decisions, according to participants, was discharging patients from physiotherapy services, as they would often not accept discharge readily, finding it very hard to come to the end of the treatment plan. Therapists felt that patients would often be unable to accept that the treatment was over and would seek another referral in the hope of continuing. In such cases, participants reported that offering a review session in a few months would often be successful in reassuring the patient. Occasionally, participants thought that therapists should just refuse continuation and use a strict approach if required to end the treatment sessions.

> "I give them a chance sometimes for another session or two but after that I will try to convince them. If they are not convinced, then I will be very harsh with them. I tell them simply: 'I can't do anything for you and you will be discharged and if you need further treatment, then you will have to obtain a new referral.'" **Ph-FG3/368**

Ph-DM-sub-theme 5: Participants' perceptions of reasons for not involving patients in making treatment decisions

This sub-theme examined participants' reported reasons for their preferences for not involving patients in making treatment decisions. Five such reasons are considered here: patients' trust in the therapist, their level of knowledge, gender, education and experience of physiotherapy.

a. Patients' trust in physiotherapists

Participants felt that patient participation in decision making might negatively affect the trust that is needed between patient and physiotherapist; the patient needed to be convinced that the physiotherapist was making the correct decisions for their specific problem. Participants reported that the feeling of being mistrusted by their patients was the most painful experience that they faced during their career as

physiotherapists. They stated that patients' doubting their decisions could be worse than them rejecting their decisions; if patients did not take the advice of their physiotherapists seriously, this could amount to disrespect of the therapists and the decisions they had made. Accordingly, participants thought that when trust and respect were not established the treatment would not be beneficial. However, they also commented that patient history might explain problems with trust in their decisions as physiotherapists.

> "Certainly, it would ensure that the patient wouldn't take you seriously. They might have well have not come to seek your advice! This type of patient will have already made up his mind about what is wrong with him. This is the worst thing the therapist could face." **Ph-FG2/431**

b. Patients' level of knowledge

Participants felt that patients did not have the knowledge or background to make clinical decisions. Physiotherapists made assessments and had the expertise and knowledge to make treatment decisions based on these, so they should have control over such decisions, whereas patients might not understand, because their level of knowledge was not advanced enough to enable them to make clinical decisions.

> "I don't think they should choose! They don't have the scientific background to agree with or dispute the physiotherapist's decision." **Ph-FG3/184**

c. Patients' gender

The participants generally agreed that female patients were usually more difficult to convince of the value of physiotherapists' decisions; they would often compare their treatments among themselves and ask for many treatment modalities. Participants therefore suggested limiting discussion and options and just giving instructions.

> **"**Female patients are more difficult in terms of participation because they always look to each other regarding the treatment and would like to have the same." **Ph-FG1/166**

d. Patients' level of education

Participants held a common view that the education level of patients influenced how much participation would be appropriate. An uneducated patient would not be able to understand very much information, so instructions should be simple and easy to understand. They felt that any discussion must suit the patient's level of education, because that would allow meaningful communication to take place. It was generally thought important to choose appropriate vocabulary when communicating with patients and that when patients were educated about physiotherapy this might make it easier to convince them and encourage them to engage with the treatment plan.

> "So if the patients' background says that he is not educated, to me, this means I should maintain a certain level of discussion with him because he won't be able to understand what I am saying." **Ph-FG1/155**
>
> **"**The level of participation, in my view, would increase with the person's education." **Ph-FG3/501**

e. Patients' experience of physiotherapy management

Participants reported that when patients had had previous experience of physiotherapy they would often ask for a certain treatment: either what they had before or something different. Therapists disliked patients comparing treatments and experiences, feeling that they might request treatments that might not be appropriate for them.

> "So if the patients' background says that he is not educated, to me, this means I should maintain a certain level of discussion with him because he won't be able to understand what I am saying." **Ph-FG1/155**

Ph-DM-theme 3: Participants' reported alternative approaches to patient participation in decision making

This theme examined participants' views on possible alternative approaches to patient participation in decision making. They expressed a preference for 'selling'

patients the treatment options they had chosen, rather than sharing the decision making with them. They proposed that physiotherapists might use a number of approaches, broadly categorised here as compromising with the patient and persuading the patient.

1. **Compromising with the patient's treatment preferences or modifying the treatment plan to suit them**

Participants thought that physiotherapists might need to compromise in their treatment decisions when the best could not be applied; this should be part of the treatment plan, as the physiotherapist has to sell these decisions to the patient successfully. However, they all agreed that compromise over what they saw as the correct treatment should be avoided. Home exercise programmes must be sold to patients so that they would be convinced and comply with them; thus, patients needed to understand the instructions and why they would lead to a certain outcome. Participants thought that patients needed to accept that there was no compromise about doing the exercises. It was pointed out that being creative with suggestions can make a big difference, as it gives patients practical ideas about how and where to do their exercises.

> "I think in a lot of cases I have found that physiotherapists talk too much. I think we give more information to our patients than any other kind of profession, so it is like we are trying to sell ourselves and our ideas." **Ph-FG2/151**

Participants thought that if necessary they would consider fitting the treatment to the work situation to make it possible for the patient to follow the exercise programme; similarly, exercises could be modified for the home environment.

> "Depending on his home environment, I would have to modify the treatment." **Ph-FG3/235**

Participants reflected that female patients could be very insistent and initially resistive to the options in the treatment plan, as they would often have had previous experiences at other clinics and would compare treatments with their past and also

with their friends. Therefore, the therapists thought that a compromise might become necessary, as long as it did not interfere with the outlines of the treatment plan. Participants thought that patients who started with their preferred treatment would often then comply with the physiotherapist's choice of treatment. This approach could thus satisfy both physiotherapist and patient.

> "I would give treatment options to patients, especially if I would like a compromise between the patient and myself. Certainly, we have a big percentage of female patients who come very frequently and are usually seen by a number of physiotherapists." **Ph-FG2/119**

Participants thought that the need for compromise could be used as a form of placebo; this might be appropriate when pain had become an issue that would prevent the goals from being achieved. Participants also thought that when a patient was in chronic pain and knew from previous history that electrotherapy could help them, then other options might not work because there would be a major psychological barrier to them. Participants suggested that initial electrotherapy could have a very effective placebo effect and allow the physiotherapist to move on to their chosen treatment option. They reported that some patients were prepared to pay for the electrotherapy or ultrasound modalities because they believed them to be vital to them. Participants also felt that patients might have a sort of psychological pain, tending to experience pain if an alternative treatment had worked well for them and if they believed that this was the only form of treatment that could help them. To compromise, this might be given as a placebo rather than as a real treatment.

> "I will try to sell the one that I believe works best for the patient. However, if they are afraid of needles, for example, then I will give them the option of trying a different treatment. But I would not say, 'What do you think of this or this?'" **Ph-FG2/157**

2. Convincing patients of the benefits of the therapist's preferred treatment

Participants believed that convincing patients was very important for treatment to succeed; a patient who was not convinced would not comply with the treatment. It was acknowledged that patients might have a problem with the perception of pain as

part of the treatment; therefore, such patients needed to be convinced that they might experience pain as part of successful treatment. Participants thought that patients who understood why the treatment plan had been devised would be more likely to be convinced.

A view among participants was that physiotherapists and patients needed to agree on treatment. If both were on the same track, then patients would be convinced, co-operate and comply with the treatment plan. Participants felt that physiotherapists might need to be creative to convince patients and to ensure that they were comfortable with the treatment plan.

> "It has to be convincing to him and it has to be convenient to him as well. If you don't convince the patient, he will not do it." Ph-**FG3/295**
>
> "Convincing the patient is more important, because my main goal is to educate the patient about his problem and most of his problems are going to be cured by doing the exercises at home, like postural corrections." **Ph-FG3/292**

Participants thought that they could convince patients by guiding them to the preferred treatment, by explaining the preferred treatment to them or by discussing it with them.

a. Guiding the patient to the therapist's preference

Participants reported that when there were alternative treatment options, the patient should be directed to the best evidence. They thought that when options were of equal value, such as for hot or cold packs, then the patient could be offered a choice. Therapists felt that it was good practice to guide the patient through the proposed home programme so that it would work for them in a practical way; patients would be more likely to follow the treatment plan if it was kept simple and short, using charts to record exercises. They thought that a passive patient was one who did not participate by complying with the instructions given by the physiotherapist.

"Unless you guide him to share the same decision you want, or direct him gradually until he has the same opinion you have." **Ph-FG3/537**

b. Explaining the therapist's preference to the patient

Participants thought that physiotherapists should listen to patients' opinions and give explanations about decisions that had been made, so that patients could understand what they were being asked to do and what they might expect. They agreed that explaining the benefits and the reasons for the choices they made could help patients to understand. They thought that physiotherapists could give such explanations as professionals with the requisite knowledge and clinical background, who were usually prepared to explain their decisions. As such, participants felt that the sequence of the treatment process might need to be explained, especially if it was not clear enough to the patient; a reasonable explanation with a clear indication of the goals would help to convince the patient.

"I should be the professional and explain why we should do this and this." **Ph-FG3/489**

"You explain to the patient, 'This is the problem and this is why we do this and not this.' Maybe that will convince the patient about why you chose what's in your plan." **Ph-FG2/348**

c. Discussing the therapist's preference with the patient

A common view was that physiotherapists could use discussion as a way of explaining the reasons for treatment choices and that patients could be invited to discuss preferences and give feedback. Participants thought that this discussion might take place between physiotherapists and patients in the following situations:

- When a patient is resistive because of prior knowledge; then discussion can explain the new procedures and decisions.
- When a patient is unable to do the exercise because it is unsuitable or unrealistic in the home or work situation; then discussion may clarify this.

- When a patient asks a specific question; discussion can then clarify how this can be addressed in relation to the treatment plan that the therapist has designed.

> "I always hear this from patients and when I discuss the goals with them and let them know what I suggest, they commonly say, 'You know so much better than I do, so please do what you decide to do. I am ready to do what you want, but the most important thing for me is to reduce my pain.'" **Ph-FG2/166**

10.5.2.2 Participants' views about the types and amount of information they wanted to give, the mode of delivery, difficulties with giving it and reasons for their preferences

The framework analysis of the themes and subthemes identified as being related to the information provision domain is presented above in Figure 11.1, page 365. These three main themes and four sub-themes concerned participants' views on the types and amount of information they wanted to give about the management of non-specific LBP, its mode of delivery, difficulties with giving it and reasons for their preferences. These are numbered below as 'physiotherapist information themes' (Ph-info-theme). Table 10.5 lists the themes and sub-themes with definitions and relates them to the aims of the focus group study.

Table 10.5: Themes and sub-themes identified from participants' views about the types and amount of information relating to the management of LBP, its mode of delivery, difficulties with giving it and reasons for their preferences

Information giving/exchange during a course of physiotherapy		
Themes/sub-themes	**Definition**	**Aims of the current focus group study**
Theme 1: Usual practice of information giving/exchange	Participants' views of usual practice of information giving/exchange when managing patients with non-specific LBP	**1**
Theme 2: Desire for information gathering	Participants' perception of LBP patients' desire for information gathering	**3**
Theme 3: Role of physiotherapists in information giving	Participants' perceptions of their role in giving information during physiotherapy to manage patients with non-specific LBP	**3**
Theme 4: Approaches to providing patients with information	Participants' perceptions of approaches that they often use to provide patients with information during physiotherapy to manage patients with non-specific LBP	**3**
Theme 5: Difficulties with giving information	Participants' views of difficulties they often face in giving information to patients with non-specific LBP	**4**

All identified codes are presented in tables listing the main sources (original focus group transcripts), themes and sub-themes identified and line numbers in the original transcripts.

Ph-info-theme 1: Participants' usual practice of information giving/exchange

This theme examined participants' views of their usual practice of information giving/exchange when managing patients with non-specific LBP. Participants reported that they would give information to their patients before or after making an assessment. They would also usually give explanations to patients, who lacked the knowledge of physiotherapists. However, they stated that they might not give detailed explanations, to avoid confusing patients with too many details; they thought that they might only be able to focus on the first part of the conversation.

> "I always try to explain so they understand what I'm doing and why I'm doing it." **Ph-FG2/427**
>
> "I always try to explain to them briefly, because sometimes patients become confused when inundated with too much information." **Ph-FG1/259**

Participants expressed the view that it was important to explain things to patients in order to educate them. They stated that they might give some information about treatment while conducting the initial discussion about a patient's back pain, then during the discussion, ideas might come into the conversation which would help to prepare the patient for receiving instructions about the home programme. Participants reported that patients often gave feedback about pain, discomfort or inability to do the exercises and this in turn might lead to further explanations being given. Feedback from conversations with their patients would also help them to make the assessment and to adapt the treatment plan as necessary.

"Would you say to the patient, 'Your problem is a prolapsed disc. What do you want to do?' No! Rather, I would say, 'You have a prolapsed disc and this is the way to treat it. I will give you this exercise in the first session and you can see the difference, if you cannot tolerate this exercise or you feel your pain is increasing, just let me know'." **Ph-FG1/40**

Ph-info-theme 2: Patients' desire for information gathering

This theme examined participants' perceptions of LBP patients' desire for information gathering. Participants felt it to be important for patients to know what the problem was. They thought that it was the patient's right to know and understand and that this might help prevention. They felt that patients should be educated and informed. They also agreed that most patients liked to know, for example, about their LBP and what caused it. However, one participant commented that some patients might ask too many questions and that some patients even asked the same questions every session.

"It is patient's right to know what the problem is and how it happened, because this will help prevent the problem from recurring." **Ph-FG1/233**

"They want to know the main problem but that's not a lot, there are only a few like this. Most of the patients would like to know the reason behind their symptoms and maybe 90% of these patients will ask for details." **Ph-FG1/233**

On the other hand, participants reported that some patients did not want information because they did not see the need; too much information could overwhelm patients. Participants also stated that some patients did not want to talk at all, only to listen, because they wanted to know only what was necessary or because they did not know what was good for them. The therapists thought that such patients generally only wished to know about the main problem and preferred not to receive detailed information. Some patients did not wish to waste time talking and just wanted treatment. Participants also referred to other patients who knew what

they wanted in terms of treatment modalities and therefore did not want information on alternatives.

> "They might pick up other little bits along the way. But a lot of information can be quite overwhelming." **Ph-FG3/465**
>
> "Some people don't want to know everything. Patients might say to you, 'I'll do what it takes, I don't need to know everything. When I am with my accountant, I don't want to know everything. I just want it done.'" **Ph-FG3/444**

Participants pointed out that men and women differed in their desire to receive information, as female patients tended to be worried about time constraints. They often wanted to obtain their treatment and finish it quickly, rather than gathering information; at the other extreme some might ask too many questions. Therapists also felt that the mood of patients could influence how much information to give and when. Some reported that they might try to read patients' body language and facial expressions to find out whether they were interested in receiving more information about the treatment, then decide what further information to give.

> "Females are more worried about time. For instance, if I want to examine a female patient's back to decide about what treatment I need to give, she would say, 'Why are you doing this? I think my doctor has already diagnosed me. I came here to get treatment.' But that is a small example compared to how much she might ask." **Ph-FG1/535**

Ph-info-theme 3: Participants' perception of their role in information giving

This theme concerned therapists' perceptions of their role in giving information to LBP patients. Participants expressed the view that they should explain to patients. They felt that their role in information giving was as educators, educating patients about their back pain problems, the treatments and self-management. They thought that it was part of patient education to inform them about the treatment options and what to expect, the reasons for the treatment choices and to how the treatment plan would work, in order to be able to give feedback about the treatment they received.

Participants considered this to be important, especially when patients were well educated, when there was a sense of obligation to give a fuller explanation because these patients would express a desire to know more about their problems. Participants thought that patients would initially need to understand the role of the physiotherapist and to learn how to use their backs correctly in future, as this would enable them to avoid possible complications. If sessions began with an explanation, patients would have a better chance of fully understanding the prescribed treatment. Participants pointed out that to state rules and give instructions without explanation might mean that patients would not comply with the treatment plan.

> "I think the physiotherapist has a big role in educating the patients." **Ph-FG3/134**
>
> "When you have some patients who are well-educated, you feel obliged to give a fuller explanation, because they would like to know about their problem, because they want to get better." **Ph-FG2/110**

Participants felt it important for patient and physiotherapist to share a goal. They thought that patients needed explanation and education so that they could understand how to achieve their goals; this would increase patients' confidence about decisions made by the physiotherapist.

> "We must explain and educate her in how to achieve her goal. If I give her the exercises and I don't explain my goal to her, she would say, 'I will not be able to do my duties at home.' She might say that there are too many exercises and so she will not do them." **Ph-FG2/238**

Ph-info-theme 4: Approaches to providing patients with information

This theme concerned physiotherapists' reports of approaches that they often used to provide LBP patients with information. Participants reported that choosing a method to educate patients must take into account the patients' social background as well as their education level; they also felt that their practice in delivering information to patients should in general be simple. Approaches to informing and educating patients about their LBP condition included talking to them and giving them verbal

explanations and instructions; educating them by conducting open days; using brochures, symbols and booklets to give background information for those who could read them; using pictures of the exercises so that patients could understand better; using pictures of the spine, charts and spine models, and describing how the movements occur; and demonstrating how the exercises should work and telling patients whether theirs was the correct position.

> "I supply them with a little chart." **Ph-FG3/286**
>
> "Booklets! Booklets at the beginning, but of course before giving them the booklets we have to explain to them some of the issues in the booklets." **Ph-FG3/383**

Ph-info-theme 5: Difficulties in giving information to patients with LBP

This theme concerned participants' views of difficulties they often faced with information giving when managing patients with non-specific LBP. They reported difficulties related to patients' level of education, to their demographic characteristics and to language differences.

1. **Patients' level of education**

Participants agreed that the patients' level of education might cause difficulties: when this was low, the physiotherapist would need to limit the information given accordingly.

2. **Patients' demographic characteristics**

Therapists pointed out that patients' demographic characteristics might affect how they gave information, offering a number of examples: if a female patient had ten children and no help at home, then treatment goals would need to be realistic and feasible for a woman who had little or no time for herself, while an elderly patient might be confused or distressed by too many instructions at once.

"You may have an old patient who is about seventy years old, so instructions to this patient might be limited. The patient might ask to only hear to a minimum, so as best to understand the instructions." **Ph-FG1/147**

3. Language differences between therapist and patient

Participants for whom Arabic was not a first language emphasised the importance of having a translator with them when giving complicated information.

10.6 Discussion

Results from these focus groups provide confirmation of the preferences of the therapists expressed in the previous survey study for patient involvement and greater detail of the reasons why they took these views. This section discusses the key findings, relate these to the existing literature and highlight a number of clinical implications of the findings. Methodological issues relating to the use of focus groups are identical to those discussed in chapter 9 and are not repeated here.

10.6.1 Summary of main findings

In general, the 18 physiotherapists who took part in the current study expressed the view that they did not favour patient participation in decision making in relation to their LBP, although they expressed a greater desire to educate patients about their LBP condition, as they felt this to be an important aspect of physiotherapy management. Many participants regarded following their clinical instructions as active participation by patients in their care. These respondents did, however, see a role for engaging patients in goal-setting, albeit while also expressed a desire to manage the goal-setting sessions and without expecting patients to then participate in decisions about management options. This suggests a traditional biomedical model of health care that encourages clinicians to adopt a more paternalistic style of decision making, believing themselves to have the clinical knowledge and authority.

Factors perceived by physiotherapists as reasons that explain their preferences for patient participation in decision making and information provision are presented in the following section, in relation to the existing literature. This involved reasons similar to those reported by patients; such as: time constraints, patients' lacking knowledge and clinical skills, possibility of losing patients' trust in their therapists. All of these factors were previously discussed as barriers to implement SDM (see chapter two and nine).

10.6.2 Discussion of main findings in relation to the literature

The results from this study identified a number of reasons for the views held by physiotherapists with respect to their preferences; the themes identified are summarised above. Discussion of their stated preferences is not repeated and is found in chapter 6 and 7.

Goal setting is one area where patient involvement is more commonly encouraged in physiotherapy practice, though our participants reported a desire to control discussion of treatment goals. They offered a number of reasons for this. They reported that giving patients the opportunity to express their preferences might encourage them to "interfere" with clinical decisions, resulting in therapists losing control. This concern reflects the work of Levack and colleagues (2011) who reported in a study of patient-centred goal-setting in rehabilitation for inpatients with stroke (n=9), by that involving patients and families in goal-setting could be unpredictable. Clinicians reported needing to regain control to ensure their preferred goals were taken forward. Leach and colleagues (2010) conducted a in a sub-acute rehabilitation setting in Australia, and results indicated that the patients' perceived inability to participate fully in the goal-setting process was the main factor that determined therapists' approach to engaging patients in the process.

Overall, the current study is aligned with much of the literature in considering time as a major barrier to patient participation; involving patients in goal-setting sessions was reported in these studies to be a time consuming procedure (Schoeb, 2009) and was suggested by our respondents as a major reason why they preferred to limit patient contribution to the discussion and setting of treatment goals.

In addition, physiotherapists thought that one reason for not involving patients in making clinical decision is that making treatment decisions should remain within their control and under their authority, regardless of the severity of symptoms or the patient's desire to be involved in making management decisions. Patients' demographic characteristics (greater age, lower standard of education and female gender) were listed among these factors, confirming results from the survey studies. Age was identified as important. Participants suggested that involving older patients in decision making was often more difficult because of their decreased intellectual abilities. These views contrast with results from a study in the Netherlands by Zandbelt and colleagues (2006) where these physicians were more likely to facilitate patient participation in decision making when they were older. .Older patients have been reported to be more passive (Nomura et al., 2007, Chang et al., 2008) and in an observational study by Zandbelt et al., (2007) physicians' approaches (inhibiting or facilitating) of patient involvement were associated with patients' information seeking behaviours. The previous chapter has noted that some patients were reluctant to ask questions about their LBP condition . (Zandbelt et al., 2007). Patients may also become rigid about changing their views or preferences and this may become more difficult for clinicians to deal with when older patients are involved (Robinson and Thomson, 2001).

Overall, the above mentioned factors are in line with the findings of Elwyn and colleagues (1999, 2000) within primary care settings.).

Participants suggested that patients who were female and had previous experience of physiotherapy to be demanding and talkative, often wanting to have similar treatments to other patients; participants perceived this as wasting their clinical time and interfering with their selection of interventions; physiotherapists perceived themselves to be time constrained due to the high load of patients. They reported that they were required to devote the first visit to making clinical assessments, whilst the following sessions were dedicated to the treatment itself. By contrast, Janz and associates (2004) found no significant relationship between length of visit and patients' preferences for a decisional role, but this relationship was not examined in relation to physicians' preferences.

Prior experience of physiotherapy, a further reason that mentioned by participants reporting is that, patient participation in decision making may lead them to ask for a replication of treatment they had had earlier or that others had received and which might not be appropriate for them now, or making them want to avoid a treatment that they thought had failed to assist their recovery. Liddle and colleagues (2007) report that patients with LBP who had experienced a variety of treatment approaches were often frustrated in finding a therapist to help them in relieving their symptoms.

Another key reason identified by this group for a limited preference for patient involvement related to 'trust'. Physiotherapists expressed strong concerns about their patient losing trust in them if they seemed unsure of what they were doing. Therefore, , some participants felt that discussing preferences with respect to treatment options might make the patient wonder whether the therapist was qualified to practice. No studies have been found that examine this issue from the perspective of practitioners from any field but Kraetschmer and colleagues (2004) found that patients' preferences for an autonomous role were associated with a low level of trust in their physicians, with a greater desire for autonomy reflecting less trust.

A key theme emerging was the role of evidence-based practice and personal experience or expertise. Physiotherapists did not consider patients to have the clinical knowledge or skills required to take part in most decision making, either about their care or information provision and type. They reported that optimum decisions should be based either on evidence or on professional experience, not on patients' views or preferences, and that it was impractical to juxtapose patients' views with therapists' clinical experience and research evidence, especially if they contradicted each other. They regarded implementing best evidence as more important than 'allowing' patients to participate in making treatment decisions about their own care. This view of evidence-based practice (EBP) as knowledge to rationalize practice (Nolan and Bradley, 2008, Barratt, 2008) encourages clinicians to use the best available research evidence when deciding about their patients' treatment options. Sackett and associates define EBP as "the judicious use of current best evidence in making decisions about care of individual patients. Its use makes diagnostic tests and

therapies more powerful, more accurate, more efficacious and safer" (Sackett et al., 1996). However, recent discussion of EBP requires practitioners to also explore patients' concerns, needs and expectations and to collaborate with them in making appropriate decisions (Epstein et al., 2004, Adams and Drake, 2006). Information from high quality clinical trials is not sufficient on its own to individualize treatment options, as patients expect and require (Chapman and Sonnenberg, 2000). This position is complex and posed questions for all clinicians; it is unclear how both approaches can be explicitly integrated within medical settings (Adams and Drake, 2006). These authors note that it is unclear how patients' and physiotherapists' roles can be integrated within the process. It is therefore not surprising that finding the balance between EBP and patient participation can be very challenging for a group of physiotherapists who generally work within a biomedical context, are not always well respected by their medical colleagues and have learned to rely on evidence relatively recently find the balance between EBP and patient participation very challenging. Our participants identified a number of practices that they believed involved patient participation in making treatment choices; these included convincing or persuading patients to accept the therapist's choice of treatment, an approach noted by Makoul (1998). The key reason provided for this was concerns that involving patients in selecting treatment options would essentially lead to poor outcomes and might harm patients. However, they saw no problem in asking patients for their preferences as to alternative locations in which to do exercises or between such interventions as cold and hot packs, suggesting that they may allow patients to participate in minor or less important decisions.

Whitney and colleagues (2008) argue that SDM need not be implemented in all clinical settings, suggesting instead a wider typology of SDM that takes into consideration the contextual factors in addition to the nature of decisions to be made, especially when multiple options do not exist. However, it was emphasized that patients should be informed by their clinicians if they were unaware of the advantages and disadvantages of the available choices.

Although participants felt that they should take responsibility for making decisions on the management of LBP, they reported greater flexibility about exchanging clinical

information with their patients. They also acknowledged the clinical significance of educating patients as part of their professional responsibilities, but gave no indication as to whether they explored patients' preferences for information prior to commencing a course of physiotherapy treatment. This finding was in common with those of primary care research concerning patient involvement in decision making (McGuire et al., 2005, Lown et al., 2009); however, participants in the present study thought that the purpose of educating patients should remain limited to increasing their awareness of their LBP and should not extend to empowering them to make management decisions. While patient education may have a positive influence self-care, the current findings suggest a low level of awareness among physiotherapists of the potential benefits of educating patients in order to improve their coping skills as a long-term outcome of physiotherapy. It has been suggested that informing patients of the benefits and risks of a particular treatment does not help to achieve better outcomes, whereas engaging patients in self-management interventions where they can participate in education programmes can help them to reach a better understanding and enhance their ability to improve their health behaviour (Adams, 2010).

10.6.3 Implications for research and practice

In the light of the above findings, this research has a number of implications to physiotherapy clinical practice:

- Study findings on reasons that perceived by physiotherapists as barriers to patient participation in decision making can be useful to inform future studies on SDM in physiotherapy context.

- The current findings highlighted the need for training, both formal and informal, to improve physiotherapists' abilities to engage patients into making therapeutic decisions related to their LBP.

- Saudi national policy and clinical guidelines should encourage more patient participation in health care; including physiotherapy practice.

10.6.4 Conclusion

The current study confirms a strong tendency among physiotherapists who manage patients with LBP in Saudi Arabia to adopt a paternalistic pattern of decision making. Reasons reported by participants included concerns that patients lacked knowledge and experience related to their condition, though it was also noted that they did not prefer to impart this information to them. They cited the importance of EBP and clinical experience for professional competence. In addition, participants expressed concerns regarding the potential negative consequences of allowing patients to share their clinical responsibilities, including a belief that this type of clinical interaction might lead to patients losing trust in them as qualified professionals.

Chapter Eleven

General discussion and conclusion

11.1 Introduction

This is the first study of patient and physiotherapy preferences for patient participation in decision making in the context of physiotherapy and in an Arabic setting, and is important both as it confirms similar results to much of that in the literature but also because it identifies a number of reasons to adopting certain preferences that are important for taking development of 'Shared Decision Making' forward. While the preceding five chapters discussed the findings of each individual study in relation to the existing evidence, this chapter identifies and discusses a number of overarching points raised by the results of the study as it addressed the key research questions, its design and it implications for practice and research.

11.2 Physiotherapy care of patients with non-specific low back pain: directions to more collaborative clinical practice

There is increasing emphasis in many health care systems on patient participation in decision making (Müller-Engelmann et al., 2011). Despite this, a growing literature on patient involvement in decision making and information provision, evidence indicates that patients and clinicians may vary in their preferences for this type of clinical practice (Robinson and Thomson, 2001, Levinson et al., 2005, Kiesler and Auerbach, 2006, Murray et al., 2007a, Murray et al., 2007b). The current thesis has confirmed this suggestion, in a series of studies, and indicates that physiotherapists' and patients' preferences, while often similar, are not always the same and a number of factors have been identified to be associated to their preferences.

Examining preferences of physiotherapists and patients with non-specific LBP was essential to contribute in addressing a number of concerns raised in the literature pertinent to managing this patient population. It occurred within the context of evidence of patients expectations of care in western settings, which suggests that

patients with LBP want their physiotherapists to individualize their treatment, offer them more time, provide them with adequate information, pay attention to their needs (Slade et al., 2009, Cooper et al., 2008) and engage them in physiotherapy plans of self-management approaches (Cooper et al., 2009, Moffett, 2002).

The current research shows that whilst participants were in agreement, for the most part, in their preferences for information provision, this agreement was noticeably decreased with regard to preferences for patient participation in decision making. Physiotherapists wanted to take charge in making clinical decisions, especially those related to choosing treatment options, whereas patients wanted an active role in making some but not all decisions. Some indicated a desire to play a more collaborative role when decisions were to be made about their home and self-management activities. However, both parties in general preferred a more passive role to be assumed by a patient when decisions are made in physiotherapy clinical setting.

Given these findings, the present thesis addresses gaps in identifying why patients want more clinical information, but do not want to participate in making treatment choices. It addresses previous research concerns that arise in the SDM literature including, Ballard-Reisch , 1990, Beisecker and Beisecker , 1990, Chang et al, 2008 and Van der Weijden et al, 2010 about why patients want clinical information and how they prefer to use it in relation to their illness. Additionally, the present findings identify when and how physiotherapists and patients with LBP thought that patients can participate appropriately in decision making and share clinical information and the reasons that were perceived by participants as either to facilitate or inhibit patient involvement in physiotherapy decision making. These results have implications to guide the development of care to manage a chronic, non-life threatening condition such as non-specific LBP. They provide evidence that patients with LBP want to exchange clinical information with their physiotherapists and to use these in managing their LBP condition when they are away of physiotherapy setting. Physiotherapists should be aware of these findings as they propose 'information exchange' that should occur in two ways between therapists and patients, as key component in designing self-management approaches. The current finding indicate that if physiotherapists are to provide care that will benefit patients with LBP, they should involve patients in

decisions affecting this in addition to utilising their clinical experiences and evidence based practice. While doing so, patients' characteristic (especially their age and those who present with psychological factors) should be taken into considerations. Further explanations on the associations of these characteristics with preferences for patient participation in decision making are provided in chapter two and the previous five chapters.

11.3 Understanding the reported preferences in relation to cultural perspectives

This study of preferences was undertaken in a unique cultural and social context relative to existing evidence, thus making and providing new insights. Previous research on patient's preferences for participation in decision making have been conducted in western countries USA, Canada, UK, the Netherlands, Germany and Australia,) and in non-western settings (Japan, Korea, Turkey and Iran (e.g. Nomura et al., 2007, Chang et al., 2008, Kara et al., 2007, Ashgari et al., 2008). This is the first study examining and comparing the preferences of patients and physiotherapists for patient participation in decision making and information provision in an Arabic setting involving work in Saudi Arabia.

Preferences are likely in part to be subject to cultural influences (Charles et al., 2006) and need to be examined within various medical contexts, health systems, cultural settings and countries. Previous work provides some indication that cultural differences are present elsewhere. Saudi Arabia is an Islamic country, and two previous studies in similar settings have noted some potential cultural influences on preferences. Kara (2007) suggest that Turkish people have 'different types' of self-perceptions from those of patients in other European countries, but provide no information about the nature of these differences. It is possible that the geographic location of Turkey between Europe and Eastern Asia has some influence on social/cultural perceptions of patient autonomy that are different from European countries. In a study from Iran, Ashghari and colleagues (2008) report that patients on 'internal' and surgical wards have a greater desire to gather information than to participated in decision making. This study from Iran suggests findings similar to those

reported in the Western countries. Whilst these countries are Islamic neither is Arabian as is Saudi Arabia; the reporting of similar results across these studies and the current study in Saudi Arabia suggests similarities across a wider geographical, yet still culturally diverse, region. While none demonstrated a strong desire for sharing decision making, the tendency for patients' in the present study to want to share decisions about their self-care may be explained by the fact that Islam encourages independence and collaboration. While it may explain patients' tendency to want to share decisions about their daily activities, it does not explain their reliance on physiotherapists to make decisions on their behalf during clinical encounters demonstrated in all three studies.

An alternative and potentially strong influence may be the dominance of the biomedical model of healthcare in Saudi Arabia (see chapter one) In addition, the absence of national health policies advocating high levels of patient participation, make it difficult to implement a collaborative model of decision making. This healthcare environment may encourage clinicians (including physiotherapists) to adopt a more paternalistic style of decision making and accordingly limit patients' contribution to the decision making process and encourage patients to act as recipients of care rather than participants. This understanding is supported by evidence from the focus group study, where patients reported not knowing that it was possible for them to express their opinions on the health care they received.

It might be expected that gender would be key issue in an Arabic setting, and that women might be more passive. Arabic societies tend to be male-dominated (Mobaraki and Soderfeldt, 2010). While the level of participation in the community and society at large by women varies across Arabic communities, it is often restricted to the family context (Littlewood and Yousuf, 2000). Many factors contribute to this, particularly with respect to women. Education for women has been very limited until recently (Mobaraki and Soderfeldt, 2010). Social structures can prevent women from being independent or engaging in physical activities (Al-Eisa and Al-Sobayel, 2012) and rely on male drivers for attendance at health care appointments due to lack of public transport and a prohibition on women driving (Mobaraki and Soderfeldt, 2010). However, gender was not demonstrated to be a key factor in determining preferences,

reflecting other studies in the field (Chapple et al., 2003, Florin, 2006); in this study, as in the literature, in general, women preferred a slightly more active role. A potential reason for this may be that in Saudi Arabia physiotherapists in general treat patients of the same gender. In addition, the design of the focus group studies, in which female and male patients were essentially interviewed separately, may have encouraged women more forthcoming in their views. Either way, provision appears to enable both genders to function in a very similar way to people in other setting.

The main results presented in this thesis provide important additions to the literature on patient and practitioner preferences, in particular with respect to preferences in non-western communities. While they demonstrate some key similarities to the exiting literature they show that preferences vary between communities. This is important not only for those working in internationally in contexts were the importance of managing non-communicable conditions is rapidly increasing but also for staff in western societies who may be working with patients from immigrant community groups.

The results also raise a number of questions. It remains unclear whether some of the differences reported are attributable to the long term nature and complexity of LBP, the multiple components of a programme of care or because of cultural differences. Much evidence to date involved a mixture of health conditions, often focusing on a single encounter and has not examined preferences for making decisions about specific aspects of care, focusing rather than overall preference. Further work is required to address these gaps.

11.4 Understanding the main findings in relation to theoretical constructs

- **Conceptual frameworks**

The current research generally reflects the conceptual frameworks underpinning models of patient involvement in decision making and information provision (see chapter two). Both physiotherapists and patients believed that the approach to decision making should be flexible, taking into account the variability in clinical circumstances (e.g. time and quality of clinical communication) ; they reported it

should be a dynamic and potentially changing process throughout the course of treatment. In addition, physiotherapists suggested various alternatives when considering treatment plans such as employing a persuasion tactic to convince patients with their therapeutic approaches. These approaches appear to match with the real situation within clinical setting and further our understanding to how patients and clinicians currently view deliberation about health-related decisions. The current findings also suggest that patient participation in decision making can take various approaches when preferences are well-defined between the two parties. According to the outcome of the qualitative phase, patient participation in decision making can be achieved through exchanging clinical information only or by discussing treatment options and expectations of the outcome. When these approaches are considered during clinical interactions between patients and practitioners, it can give more flexibility to implementing SDM (see chapter two) and widen the knowledge of the steps that are preferred by both parties.

- **Theoretical explanations**

The Self-regulatory Model (SRM) propose that emotional, cognitive and physical constructs are often affected by one's illness (Leventhal et al., 1997, Leventhal et al., 2003). These constructs are: the individual's perceptions of susceptibility to an illness, of the severity and threat of the health condition, of the benefits of taking a particular action to avoid or overcome the health threat and of the barriers to taking such action. As a chronic and potentially disabling condition with a complex clinical presentation, LBP demonstrated a similar a response to health threats caused by an 'illness' as described here (Keefe and Dolan, 1986, Keefe et al., 1990, Boston and Sharpe, 2005). Patients' preferences to play a more passive role in making decisions on managing their LBP can be attributed to the low confidence or decreased self-efficacy in patients' abilities to manage their health (Jensen et al., 1991, Makoul and Clayman, 2006). As a consequence of this threat, patients may seek new representations of their illness; these were referred to as 'coping strategies'. This adoption of certain strategies for coping with LBP may result from patient low perception of self-control over the illness and therefore they may tend to seek the help of a physiotherapist and become less likely to believe in their own ability to overcome their health problem.

To illustrate, LBP can results in increasing disability and exacerbates negative psychological manifestations, such as anxiety, fear of movement and depression (Foster et al., 2008, Foster et al., 2010). As a chronic illness, these features of LBP have the potential to influence patients' perceptions of LBP consequences, their abilities to control symptoms and expectations of clinical outcomes (Scharloo and Kaptein, 1997). These represent the emotional and cognitive constructs of the SRM, while its physical construct is delineated as patients with LBP develop avoidance behaviours that result from pain-related fears (Huijnen et al., 2011). This leads to new representations of the illness (coping strategies). For example, the complex and persistent symptoms of LBP can interfere with the cognitive abilities of patients to manage their condition (Apkarian et al., 2004), and accordingly impair their self-control over their condition and their ability to make management decisions. Therefore, patients may seek support from their environment, including the physiotherapist and physiotherapy care (Gatchel, 2004). As such, patients may tend to rely on others in making treatment decisions and thus avoid taking responsibility (passive coping). However, the responses obtained from the focus groups suggest that the level of a preference for taking responsibility varied according to the nature and degree of the perceived level of responsibility (or importance) of the decision.

The current study regarding decisional roles confirms Makoul's hypothesis of the concept of **'reliance orientation'**, where patients can be divided into two types: 'clinician-reliant' (external, other controlling) and 'self-reliant internal, (self-controlling)' (Makoul, 1998). Thus, patients' ability and readiness to be responsible for deciding on finding clinical solutions may be influenced by their perceptions of self-control over their health/illness. As in other studies, the current findings found that patients who were more affected (either physically or emotionally) preferred to have treatment decisions made by the therapist (passive role), while the less affected patients tended to prefer making their own choices (active role) (Stiggelbout and Kiebert, 1997, Arora and McHorney, 2000, Adams et al., 2001, Stiggelbout et al., 2004, Chang et al., 2008).

The findings of this thesis suggest a desire for some level of 'self-management', with patients keen to make decisions about their care in home settings. However, 'self-

management' has been reported by patients with LBP to be a major challenge (Slade et al., 2009, Liddle et al., 2007) and current evidence suggests that some individuals need more support than others, due to low personal confidence and weak self-regulation (Foster et al., 2010). One way to support self-management can be through shared decision making. Moffett (2002) emphasises the need to engage patients actively and to encourage independence in approaches to manage LBP, encouraging patients to share the responsibility for deciding (or make decisions) about how to manage their condition after providing them with the necessary information. When patients are prepared to take part in deciding about the options for managing their LBP, this can potentially reduce the psychological impact of the condition and improve outcomes (Hack et al., 2006), while engaging them in understanding their condition and providing them with information can promote their ability to solve their own health problems. Patients who participated in the current research suggested that engaging them in decision making could assist their abilities to self-manage their LBP, meet their needs, increase their emotional self-capacity to manage their concerns about complications and learn more positive coping strategies on a day to day basis. Further research work however is needed to examine if and how defining patients' preferences and engaging them in their management of their LBP can play a role in increasing their self-efficacy.

Using an a psychological intervention that was based on the common-sense self-regulation model, Phillips and associates (2011) state that professionals' awareness of the SRM related behaviours can be effective in any intervention approach to improve patients' adherence to care. it is important for physiotherapists to understand patients' individual experiences with their LBP and the variations in illness representations that patients may present as a 'multi-level framework' in order to guide and engage them in the management process over time (Hale et al., 2007). In the present research, patients expressed a sense of feeling empowered when listened to; they wanted an ongoing dialogue with their physiotherapists as this gave them the opportunity to share their concerns about their LBP condition and reduced their anxiety about LBP. This level of communication can empower patients to gain more self-confidence and rely more on themselves instead of relying completely on their physiotherapists.

Information gaining can be used to promote communication and correlates patients' understanding and ability to recall information with their treatment compliance (Ogden, 2007). In that sense, patients' self-perception of their illness and expectations of treatment plans and outcomes can be directly related to information provision as it appears to facilitate the implementation of SDM. Information can influence patients' perceptions by either increasing or decreasing their anxiety or fear of movement. However, patients' attitudes can change as a result of having different ideas or information about particular topic; this is often related to someone's individual cognitive ability to break any information into small parts, each of which has its own value and weight (Anderson and Yu-Min, 1991).

11.5 Strengths and limitations of the current approaches to research in the field

The methodological approaches taken and tools used to examine preferences in health care are very varied. This diversity of approaches to evaluate patient involvement in decision making and information provision has led to difficulties in replicating, comparing and generalizing the results obtained (Dy, 2007, Simon et al., 2007).

A number of key factors appear to have contributed to this. Historically, decision making was dominated by a strongly quantitative approach, with the development of decision making tools and aids, often based on algorithms, to assist both practitioners and later patients make decisions, most often about either a diagnosis or a treatment (Patel et al., 2002, Kaplan and Frosch, 2005). Much of the literature since then, examining decision making and preferences, has focused on the two domains of interventions and treatment aspects. Although the more recent literature (e.g. LeBlanc et al., 2009, Leach et al., 2010, Légaré et al., 2011) have expanded their focus, other aspects of patient involvement in decision making remain relatively neglected.

Two major factors affecting the current research in the field follow on directly from our discussion of the conceptual frameworks underpinning the field, and the role of theoretical models in explaining and underpinning preferences, be they those of patients or therapists, as part of decision making. A lack of consensus on the definition of patient involvement in decision making (see chapter two) has compounded the

problem and also resulted in difficulty in identifying optimal approached examine it (Dy, 2007).

Conceptual frameworks of SDM and 'preferences' are described in chapter two and it is clear that they both interrelated to each other and that they are continually evolving as studies are undertaken. However, the concept of 'preferences' is not well-defined in the existing models of patient involvement in decision making. These changes and development have resulted in few, and sometimes disparate, studies being available in some key areas while other aspects are more extensively and completely investigated. Despite, these problems there are important benefits. These are seen in that the field has developed and expanded to encompass increasing domains as they become more evidently important. Patient preferences, along with concepts such as SDM, are relatively recent concepts within health care, being related to the increasing introduction of the biopsychosocial model of care; they are increasingly seen as core to effective, evidence based practice.

The recent recognition of the need to consider the impact of participants' attitudes and beliefs on behaviours is also key to variation in approaches taken to investigate patient participation in decision making. Models, such as the self-regulatory model, are now increasingly underpinning the studies undertaken, the types of tools employed and the topics addressed (Sivell et al., 2011). Again, the impact of preferences on decision making is increasingly being recognised as key to success and is increasingly coming to the fore. Most, if not all, of these models are derived from the psychological literature, and the relatively recent recognising of the need for such models to inform decision making required discussions between experts from across subject boundaries; so, for example, it is only very recently that physiotherapists are begun to recognise the important of attitudes and preferences (previously seen as the domain of psychologists) in health behaviours.

This evolving research field has resulted in the level of work in various areas being very varied. In fields such as communication a reasonably well developed literature exists that can both applied to the field of preferences, including preferences for information provision (Manson, 2010, Main and George, 2011) while others such as participation

in making decision about various aspects of patient healthcare (not only treatment options) are very scant.

A final issues related to the current research in the field relates to the design of studies. Methodological issue have been considered extensively in chapter two. As noted in chapter four, these measures have been largely developed in primary care settings, often involve a single consultation and were often focus on making choices about treatment options rather than aspects of the whole process of decision making. Very few involve evaluation of preferences. The need to investigate 'real life' decision making is important and observational studies have been employed to examine behaviours; they are not however appropriate to collect information about on preferences (Bowling, 2009). To achieve this requires investigation through self-report, most often using surveys and focus groups. One key problem encountered with this is the issue of examining preferences in a 'hypothesised situation' - either using vignettes or other types of cases – or asking about more general preferences outside a specific context. Both can distort responses. However, it is also important to examine preferences across wider populations in order to be able to extrapolate results more widely to larger populations and into other contexts. Such difficulties are not uncommon in health care research but add complexity and have resulted in limited understanding of preferences to date.

Finally, difficulties arise with implementing the findings of some of this work in the practice setting. Limited or incomplete information can make it difficult to know how best to introduce the concepts into practice. Education of therapists (practitioners) in general has not considered until very recently the importance of concepts such as preferences in managing and educating patients, and there is some evidence that they need to understand the concepts principles underpinning their role in care to be willing to implement them (Légaré et al., 2012). The current studies on SDM competencies; including defining preferences of both patients and practitioners tend towards practitioners making key decisions, guiding the process of decision making, with practitioners in particular being strongly resistant to 'allowing' patients to take an active role. Much more work is required to examine ways of supporting health (Légaré

et al., 2011)practitioners to understand and critical implement new research findings in the context of their practice.

11.6 Research strengths and limitations of current studies

In addition to the methodological critique presented in the preceding five chapters, this section presents thesis overall strengths and limitations.

11.6.1 Research strengths

Research Rationale: A key strength of the current study is the range of aspects investigated in a new field; the first study of its kind set in Saudi Arabia; the first to explore the preferences of physiotherapists and of patients with LBP for patient participation in decision making and information when managing non-specific LBP; a single health condition. This enabled a more homogeneous sample who shared a common ground of illness severity and perhaps similar potential problems to be studied. As noted in chapter three, the severity of illness may influence patients' and clinicians' preferences for patient participation in decision making and this may be seen as weakening the internal validity of other studies whose designs involved heterogeneous samples (Bowling, 2009). Such unique features offers new insights into developing a better management of patients with LBP in the physiotherapy setting and more effective interactions between patients and therapists.

Research design: The mixed method approach used here is also rare with most other studies using either qualitative methods (to examine clinicians' views) or quantitative methods (to examine patients' preferences). Two research methods were employed in a complementary explanatory sequential design (Ivankova et al., 2006) and this allows a more holistic conclusion from data of patients and therapists preferences and in-depth examination of patients' and physiotherapists' views of reasons for their preferences. This involved a cross-sectional questionnaire survey followed by focus group studies to explain the results of the survey. In addition, conducting the pilot study helped the researcher to explore the research environment and this assisted in making a plan to select and approach study sites while being aware of potential

difficulties in collecting data (Bowling, 2009). The pilot study also facilitated the recruitment of participants, as it familiarised the researcher with the research environment and assisted her in accessing physiotherapy facilities.

11.6.2 Research limitations

Notwithstanding the above strengths, the current research has its limitations, concerning design, coverage and bias.

Research design: A potential source of bias in this study arises from the way the questionnaires were distributed. Patients who participated received the questionnaires and returned them to the environment in which they had received their physiotherapy programme. This may have influenced their responses to some questionnaire items as they may have felt under pressure to give positive views about their physiotherapy care. In order to limit this potential bias, the patients were assured that their participation was anonymous and that no information about their participation would be passed to any staff member, including their physiotherapists. However, few of the respondents had not have any experience of being involved in research and this in itself may have led them to feel embarrassed or inhibited.

In addition, the validity of the conclusions drawn from the qualitative study may be seen as limited to the study population as the number of participants was small and should be treated with caution without further evaluation (Creswell, 2009, Krueger and Casey, 2009). However, data were frequently checked for saturation until no further new ideas are raised during the discussions (Krueger and Casey, 2009).

Sample coverage: Although the sample covered three main cities of Saudi Arabia, it may not be representative of the whole Kingdom, as other cities in the north and south of Saudi Arabia were not involved in the current research. The reason was mostly pragmatic: as is common with this kind of academic research, the timeframe was limited. However, a wide range of the Saudi population do live in the cities involved and Saudi citizens from all over the Kingdom have access to the large number of hospitals located in Riyadh city, from which the three participating hospitals were selected (see chapter three).

Because the patient questionnaire was written, the quantitative phase of the current research was limited to literate patients; however, the focus group studies involved both illiterate and literate participants, in order to extend the sample and make it more representative of the Saudi population.

Measurement bias: Because this study involved survey questionnaires, measurement bias was possible at the early stage of developing the questionnaire and structuring the items (Oppenheim, 1992). To address this, a comprehensive pilot phase was employed to validate the questionnaires. Items were tested for face and content validity, including acceptability, wording, clarity, relevance and scoring mode. In order to minimize the level of bias when completing the questionnaire, participants were also informed that there were no right or wrong answers. To reduce recall bias (Bowling, 2009), they were asked to report only their most recent experience of managing LBP in a physiotherapy setting regarding decisions made and information shared, and this part of the questionnaire was distributed towards the end of the physiotherapy programme, rather than immediately after treatment sessions.

11.7 Future studies

Given that this is the first study of its kind and very little else on this topic exists in the physiotherapy literature, the scope for future work is extensive. However, a number of key issues require future study. First of all, because LBP is often associated with psychosocial manifestations that may influence patients' perceptions of their self-control over their illness, it would be beneficial if both self-efficacy and coping strategies were assessed together with patient preferences for participation in decision making and information provision. In addition, examining the role of patient involvement in decision making while providing them with the level and type of information they prefer on patient self-efficacy is key to effective self-management and adherence to care plans. While facilitators and barriers to implementing the SDM model have been examined in some fields, none have been identified within physiotherapy settings when managing patients with LBP. The used questionnaire could be refined and shortened but further validation studies would be required for this. Finally studies are still required to examine the influence of patient preferences

for involvement in decision making and information provision on treatment outcomes and on patients' adherence to treatment plans. While there are studies addressing many of these aspects in fields other than physiotherapy, those doing so in countries such as Saudi Arabia appear to be lacking.

11.8 Final conclusion

Physiotherapists' and patients' preferences for patient participation in decision making and information provision are similar in many ways but not identical. While patients wanted some active and collaborative role in deciding about self-related activities, physiotherapists demonstrated a strong paternalistic style of decision making. However, both participants were in agreement, to a large extent, in their preference for giving/gathering clinical information.

Patients with non-specific LBP expressed a higher desire to gather information than participating in making care decisions. Reasons underlying this preference indicated patients' wishes to use the gathered information to increase their abilities to self-manage their LBP condition as well as avoiding further complications. This suggests a desire of patients to be confident, empowered and supported to self-manage their LBP in the non-clinical context (for example, at home or in the community).

While the study questionnaires were constructed for a research context, they could be adapted and used within any physiotherapy encounters (not just managing patients with LBP) to explore SDM in physiotherapy research and practice in Saudi Arabia, and other Arabian countries and to be used as basis to inform developing similar tools internationally.

Finally, this thesis provides support for physiotherapy management of patients with LBP to move away from the biomedical model of healthcare towards a more collaborative model that consider patients' values, concerns and preferences.

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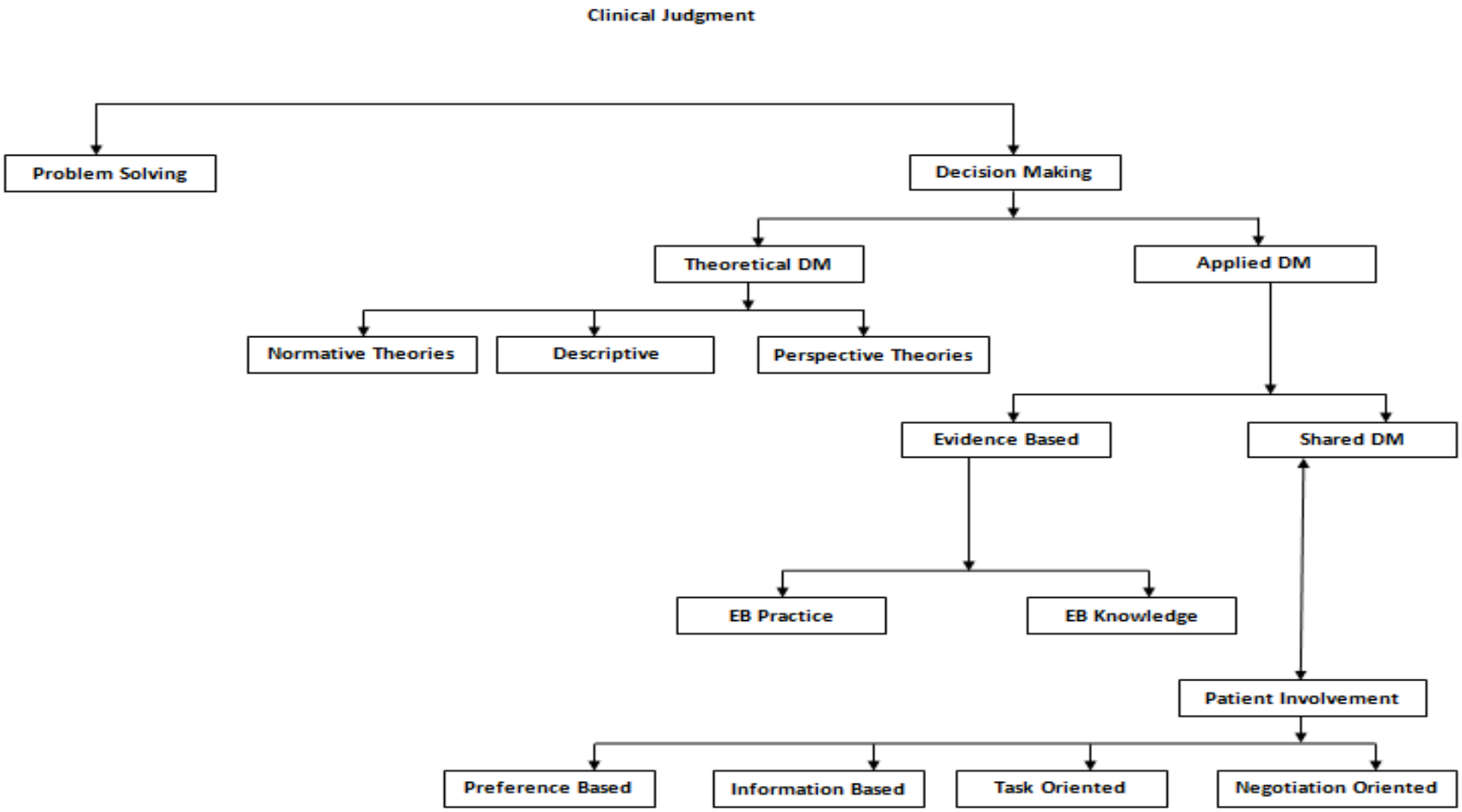
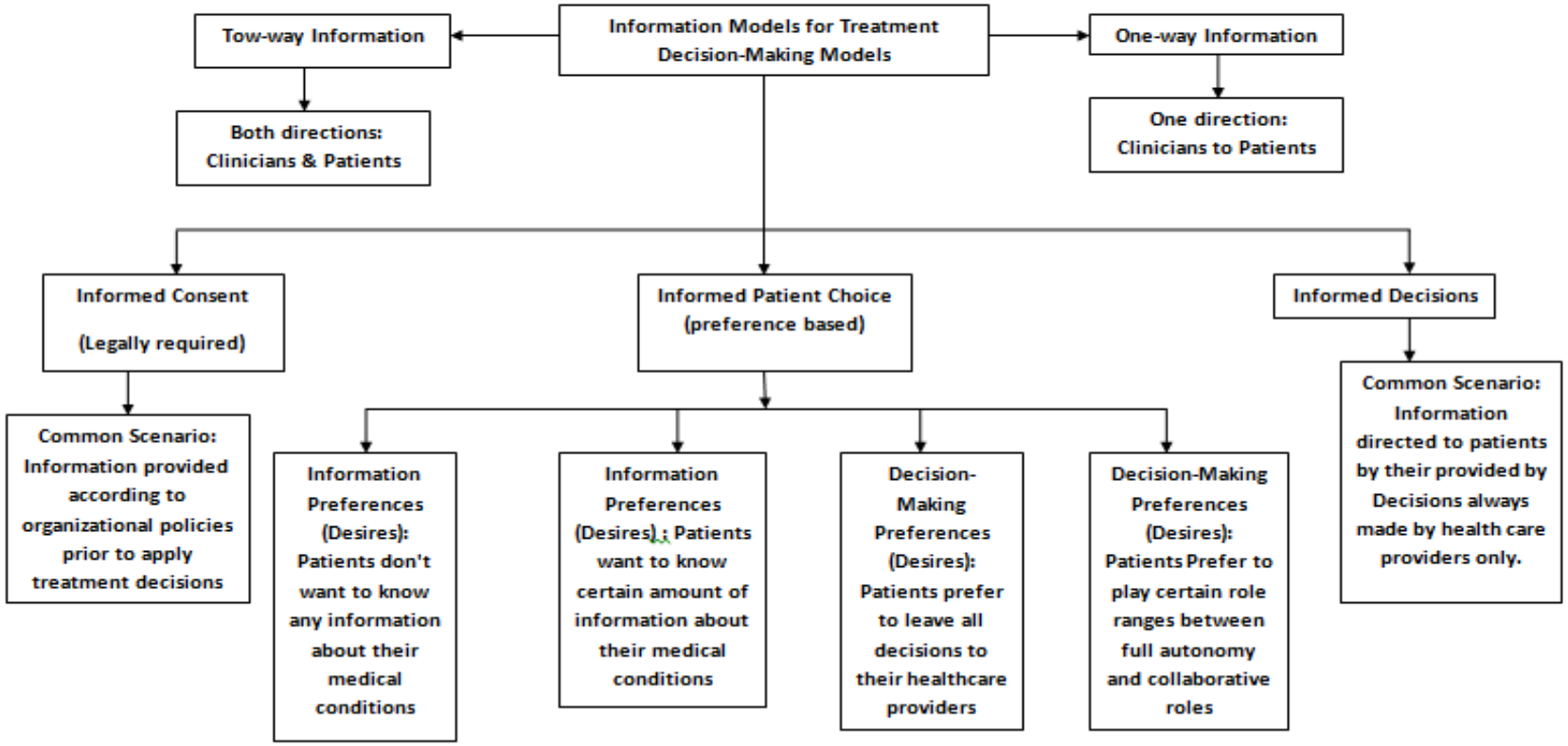
APPENDICES

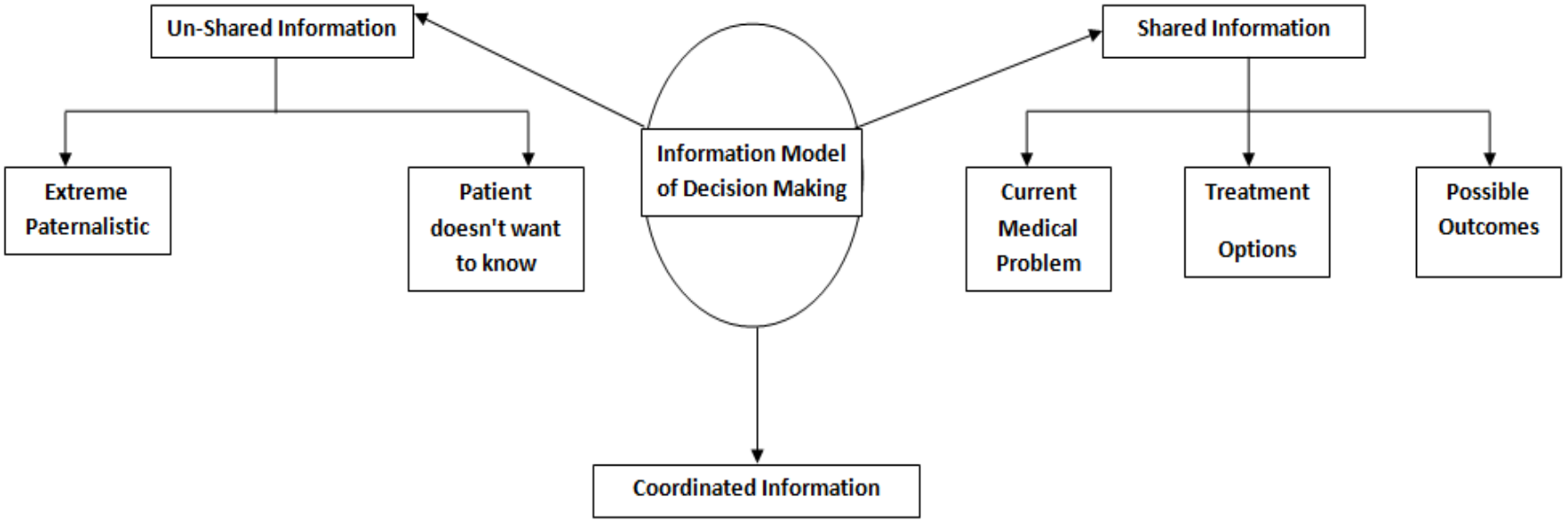
APPENDIX 1.1

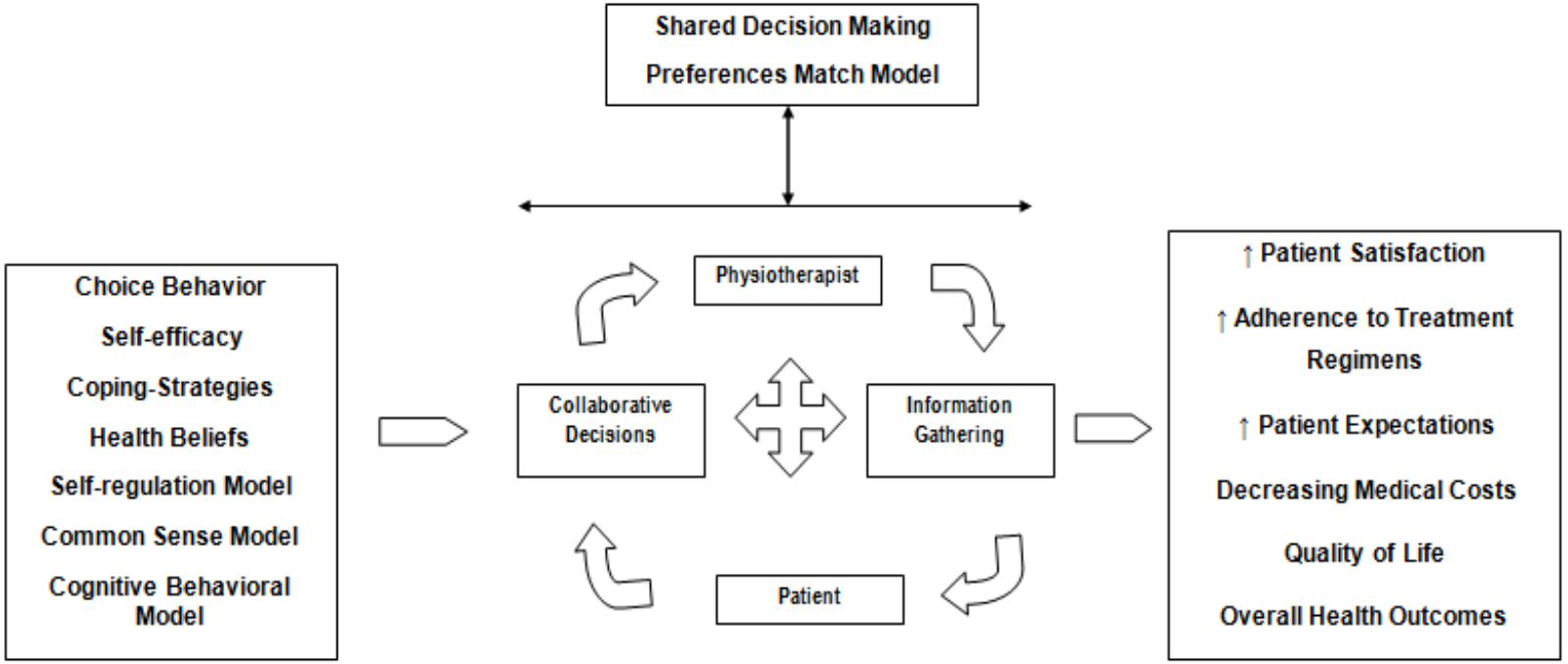
Figures illustrating the researcher's initial thoughts about the current research topic

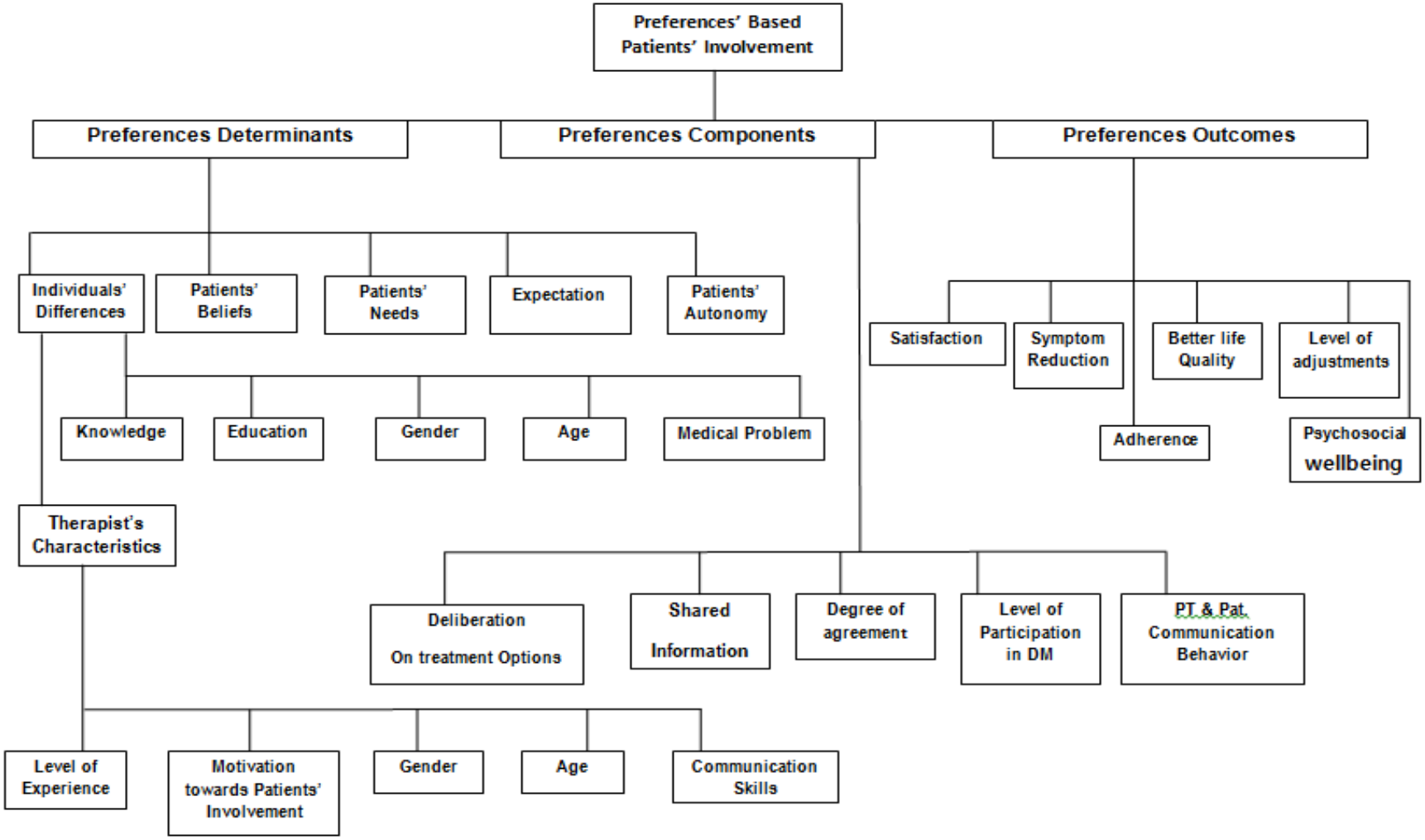

Clinical Judgment
Problem Solving
Decision Making
Theoretical DM
Applied DM
Normative Theories
Descriptive
Perspective Theories
Evidence Based
Shared DM
EB Practice
EB Knowledge
Patient Involvement
Preference Based
Information Based
Task Oriented
Negotiation Oriented

Information Based Decisions (Single Clinical Consultation)




Un-Shared Information
Shared Information
Extreme Paternalistic
Patient doesn't want to know
Information Model of Decision Making
Current Medical Problem
Treatment Options
Possible Outcomes
Coordinated Information


Shared Decision Making
Preferences Match Model
Choice Behavior
Self-efficacy
Coping-Strategies
Health Beliefs
Self-regulation Model
Common Sense Model
Cognitive Behavioral Model
Physiotherapist
Collaborative Decisions
Information Gathering
Patient
↑ Patient Satisfaction
↑ Adherence to Treatment Regimens
↑ Patient Expectations
Decreasing Medical Costs
Quality of Life
Overall Health Outcomes


Preferences' Based Patients' Involvement
Preferences Determinants
Preferences Components
Preferences Outcomes
Individuals' Differences
Patients' Beliefs
Patients' Needs
Expectation
Patients' Autonomy
Satisfaction
Symptom Reduction
Better life Quality
Level of adjustments
Knowledge
Education
Gender
Age
Medical Problem
Adherence
Psychosocial wellbeing
Therapist's Characteristics
Deliberation On treatment Options
Shared Information
Degree of agreement
Level of Participation in DM
PT & Pat. Communication Behavior
Level of Experience
Motivation towards Patients' Involvement
Gender
Age
Communication Skills

APPENDIX 2.1

The most cited examples of Patient Involvement Models

Table: Informed decision making elements

Braddock et al. (1997)	**Braddock et al. (1999)**
1. Discussion of the clinical issue and nature of the decision to be made 2. Discussion of the alternatives 3. Discussion of the pros (or benefits) and cons (or risks) of the alternatives 4. Discussion of uncertainties associated with the decision 5. Assessment of patient's understanding 6. Asking the patient to express a preference	1. Discussion of the patient's role in decision making 2. Discussion of the clinical issue or nature of the decision 3. Discussion of the alternatives 4. Discussion of the pros (or benefits) and cons (or risks) of the alternatives 5. Discussion of uncertainties associated with the decision 6. Assessment of patient's understanding 7. Exploration of patient preference

Table: Competencies of informed SDM

1. Develop a partnership with the patient
2. Establish or review the patient's preferences for information
3. Establish or review the patient's preferences for role in decision making
4. Ascertain and respond to patient's ideas, concerns, and expectations
5. Identify choices
6. Present (or direct patient to) evidence, taking into account competencies 2 and 3, framing effects. Help patient to reflect on and assess the impact of alternative decisions with regard to his or her values and lifestyle
7. Make or negotiate a decision in partnership with the patient and resolve conflict
8. Agree an action plan and complete arrangements for follow up.

Table: SDM characteristics

• Shared decision-making involves at least two participants—the doctor and the patient—and often many more (their respective networks of family or professional colleagues).
• Both parties (doctors and patients) take steps to participate in the process of treatment decision-making.
• Information sharing is a prerequisite to shared decision making.
• A treatment decision (which may be to do nothing) is made, and both parties agree to the decision.

Table: Competencies in the SDM Model

1. Implicit or explicit involvement of patients in decision-making process.
2. Explore ideas, fears, and expectations of the problem and possible treatments.
3. Portrayal of equipoise and options.
4. Identify preferred format and provide tailor-made information.
5. Checking process: understanding of information and reactions (e.g. ideas, fears, and expectations of possible options).
6. Checking process: acceptance of process and decision-making role preference, involving the patient to the extent they desire to be involved.
7. Make, discuss or defer decisions.
8. Arrange follow-up.

Table: An integrated model of SDM

Essential elements	
Define/explain problem	
Present options	
Discuss pros/cons (benefits/risks/costs)	**General qualities**
Patient values/preferences	Deliberation/negotiation
Discuss patient ability/self-efficacy	Flexibility/individualized approach
Doctor's knowledge/recommendations	Information exchange
Check/clarify understanding	Involves at least two people
Make or explicitly defer decision	Middle ground
Arrange follow-up	Mutual respect
	Partnership
Ideal elements	Patient education
Unbiased information	Patient participation
Define roles (desire for involvement)	Process/stages
Present evidence	
Mutual agreement	

APPENDIX 4.1

Descriptions of instruments developed and tested to examine patient involvement in decision making and information provision

Tables 1-3

Table 1: Descriptions of instruments developed and tested to examine patient involvement in decision making

Instrument Author/ Year of Publication	Country	Aim	Original method of administration	Original study setting and study population	Approach to item development and selection	Description of the items
Patients' Perceived Involvement in Care Scale (PICS) (Lerman et al., 1990)	USA	To assess patients' perceptions of patient-doctor communication towards involvement and information	Patient self-administered measure	Outpatient sample of patients with breast cancer (n=131)	Consultation of experts, relevant literature, physicians' survey and observation of doctor-patient interaction during consultations	13 items indicating obvious behaviours of patients and physicians perceived by patients during routine outpatient encounters. Patients answer with 'yes' or 'no' to reflect their perceptions. Available in English & German. A modified version was validated to be used among patients with persistent pain (Smith et al., 2006).
The Desire for Involvement Questionnaire (DIQ) (Thompson et al., 1993)	USA	To evaluate desires for involvement in medical treatment decisions	Mailed questionnaires	Participants were Health Maintenance Organization members (n=459)	Based on relevant literature and other instruments	Four vignettes describing medical problems at various levels of severity: knee injury, high blood pressure, a cancerous growth and stress headaches. Two treatment options are provided. These are medically appropriate but varied in their influences on patients' lifestyle and potential side effects. Patients are asked to imagine the situation of being asked: 'Who should decide which treatment programme you receive?' Response mode is similar to the Autonomy Preference Index.
Patient Preference for Control (Bradley et al., 1996)	USA	To assess level of control that patients prefer in making decisions	Patient self-administered measure	Adult patients at family practice residency clinic (n=71)	Medical scenarios were adapted from relevant literature and other instruments	A questionnaire with one general question and 10 various medical scenarios presented with 7-point Likert scale indicating passive, collaborative and active role. Responses show different levels of control & patient's preference for information and DM by placing various degrees of emphasis on either the physician or the patient.

Table 1 cont.: Descriptions of instruments developed and tested to examine patient involvement in decision making

Instrument Author/ Year of Publication	Country	Aim	Original method of administration	Original study setting and study population	Approach to item development and selection	Description of the items
The Satisfaction with Decision Scale (SWD) (Holmes-Rovner et al., 1996)	USA	To evaluate satisfaction with decisions made about hormonal replacement therapy	Patient self-administered measure	Women 40 years and older (n=252) Context: postmenopausal hormone-replacement therapy	Not explicitly clarified by authors	Six items evaluate patients' satisfaction with healthcare decisions. The response mode is 5-point scale ranging from 'strongly disagree' to 'strongly agree'.
Participatory decision-making style (PDMS) (Kaplan et al., 1996)	USA	To evaluate patients' self-rating of physicians' propensity to involve patients in decisions	Patient self-administered measure	physicians (n=300) with various medical backgrounds & patients (n = 7730) in primary care/outpatient settings	Not described, but mentioned that the three questions are included on patients' screening questionnaire.	Three questions with a five-point scale. The core of the three questions is to ask patients whether their physicians encourage them to take part in making treatment decisions or not.
Decision Self Efficacy Scale (DSES) (Bunn and O'Connor, 1996)	Canada	To evaluate self-confidence in ability to make decisions	Patient self-administered measure	Women having hormone replacement therapy (n=60)	Based on decisional conflict scale and Bandura's concept of self-efficacy (Bandura, 1977)	It focuses on social aspects of making decisions when information is provided. An 11-item scale presented with a five-point Likert scale from 'no confidence' to 'full confidence'.

Table 1 cont.: Descriptions of instruments developed and tested to examine patient involvement in decision making

Instrument Author/ Year of Publication	Country	Aim	Original method of administration	Original study setting and study population	Approach to item development and selection	Description of the items
Control Preference Scale (CPS) (Degner et al., 1997)	USA	To assess the amount of control patients prefer to have when deciding about their treatment	Cards that indicate the most preferred decisional role	Nursing context: A longitudinal study (n=436, n= 150 and n= 1,012) on newly diagnosed patients at outpatient oncology clinics & women with breast cancer	Based on a grounded theory that emerged from a number of qualitative studies and literature on patients' preferences for treatment decisions.	A set of five cards which contains statements representing patients' role of involvement in treatment decisions. Each card shows the role most preferred by a patient. The five roles are presented with a hierarchy from most to least preferred role. Widely used in research settings and available in English and other languages.
Provider Decision Process Assessment Instrument (PDPAI) (Dolan, 1999)	USA	To evaluate decisional conflict from clinicians' point of view	Clinician self-administered measure	Patients at Internal Medicine Clinics (n = 112)	Adapting 12 items of decisional conflict scale	A 12-item scale with response format of a 5-point scale. Items are similar to those in the decisional conflict scale but reflect decisional issues from the clinician's perspective.
Facilitation of Patient Involvement Scale (FPIS) (Martin et al., 2001)	USA	To evaluate patients' perception of whether physicians encourage their involvement in health care	Patient self-administered measure	College staff members (n= 236) (n=338)	Based on reviewing relevant literature & feedback from 17 expert psychologists and four general medical practitioners.	A 9-item scale to assess patients' perception of involvement in health care. Statements were directed either in the negative or positive direction. The response mode is a 6-point Likert-type scale ranging from "none of the time" to "all of the time".

Table 1 cont.: Descriptions of instruments developed and tested to examine patient involvement in decision making

Instrument Author/ Year of Publication	Country	Aim	Original method of administration	Original study setting and study population	Approach to item development and selection	Description of the items
Decision Regret Scale (DRS) (Brehaut et al., 2003)	Canada	To evaluate decisions after they have been made at a certain time	Patient self-administered measure	Four studies in contexts of hormone replacement therapy (n= 177), patients with breast cancer (n= 395), women to decide between lumpectomy and mastectomy (n= 200) and men with prostate cancer (n= 56).	Theories on "regret" concept were reviewed. A pilot version was constructed by a group of decision experts and health practitioners.	A scale of five statements presented with a five-point Likert scale ranging from 'strongly disagree' to 'strongly agree'. The statements indicate whether the decisions made were right, wise or caused a lot of harm and whether the patient would make the same decision if asked to decide again. The scale is available in English and German (Simon et al., 2007).
Combined Outcome Measure for Risk Communication and Treatment Decision-Making Effectiveness (COMRADE) (Edwards et al., 2003)	UK	To assess risk communication and DM effectiveness	Patient self-administered measure	Patients in primary care practice (n=960)	A systematic review of relevant literature & data from focus groups with health consumers. Items were adapted and piloted in the context of UK primary care	A 20-item scale to assess risk communication during primary consultation regarding patients' satisfaction and confidence. The first factor was termed "risk communication" as its items address information content and exchange.
Rochester Participatory Decision-Making Scale (RPDMS) (Shields et al., 2005)	USA	To measure patient-physician behaviour in collaborative DM	Observation using audio recordings	Recorded encounters (n=193) standardized patients (n=5) & primary care physicians (n=100)	Using model of informed DM by (Braddock et al., 1999) & other literature	Nine items addressing physicians' behaviour as to whether patients are encouraged to participate in DM during primary care medical encounters.

Table 1 cont.: Descriptions of instruments developed and tested to examine patient involvement in decision making

Instrument Author/ Year of Publication	Country	Aim	Original method of administration	Original study setting and study population	Approach to item development and selection	Description of the items
Shared Decision Making Questionnaire (SDM-Q) (Simon et al., 2006)	Germany	To measure the process of SDM from patients' viewpoint	Self-reported questionnaire	Patients with depression, gynaecology, general practice, urology & anaesthesia (n=773)	Development process was driven by steps, skills and competences of other measures that aimed at understanding and conceptualizing different aspect of SDM in addition to theories from different psychosocial backgrounds.	- It was initially developed in 24 items in German, then reduced to 15 items using Rasch model of analysis in order to establish its psychometrics. - Response mode of 4-point Likert scale. - Further refinement revealed additional reduction where 11 items remained. - Process of extracting and implementing information used in development and item construction not clarified by authors. - Available in German & English.
The 9-item Shared Decision Making Questionnaire (SDM-Q-9) (Kriston et al., 2010)	Germany	To address problems with establishing psychometric properties of SDM-Q	Self-reported questionnaire	Mainly German patients in primary care (majority over 60 years old) (n=2351)	The SDM-Q was revised thoroughly using classical test theory to calculate tests outcomes. 26 new items were generated and response mode was changed to 6 points. Cross-validation technique was applied to the results of two sub-groups where the SDM-Q-9 was developed.	- Nine items, one for each step of the SDM process proposed by authors. These items are intended to be rated by patients after their medical consultations.

Table 2: Descriptions of instruments developed and tested to examine patient involvement in information provision

Instrument Author/ Year of Publication	Country	Aim	Original method of administration	Original study setting and study population	Approach to item development and selection	Description of the items
Preferences for Information (PFI) (Hack et al., 1994)	US	To assess patients' preferences for treatment-related information	Cards to indicate information preference	35 women with breast cancer. Medical oncology and radiation oncology clinics	Literature review of relevant studies	A set of card-sort techniques to assess patients' preferences for information related to their condition, diagnosis, treatment, side effects and prognosis.
EORTC questionnaire (Arraras et al., 2004) (Arraras et al., 2010)	UK & other European countries	To assess information received by patients with cancer throughout their medical management	Patient self-administered measure	A longitudinal study involving patients with various types of cancer	Professionals from a number of European regions developed this questionnaire based on guidelines of European Organisation for Research and Treatment of Cancer & on semi-structured interviews with clinicians and patients	26 items (reduced to 25) involving information about the disease, medical tests, treatment and other services. The response mode for most of the items is a 4-point Likert scale (1 – not at all, 2 – a little, 3 – quite a bit, 4 – very much); other items have 'yes' or 'no' responses.

Table 3: Descriptions of instruments developed and tested to examine patient involvement in decision making and information provision

Instrument Author/ Year of Publication	Country	Aim	Original method of administration	Original study setting and study population	Approach to item development and selection	Description of the items
Autonomy Preference Index (API) (Ende et al., 1989)	USA	To measure patients' preferences for autonomy in information and participation in treatment decisions	Patient self-administered measure	Patients in primary care clinics (n=312)	Delphi method: professional consensus of physicians treating patients in primary care	A scale of 0-100 items includes three medical vignettes indicating the severity levels of certain medical illnesses: upper respiratory tract illness, hypertension and myocardial infarction: 0 indicates lowest level of desire, 100 indicates a very high preference and 50 indicates a neutral choice. The response mode is 5-point Likert scale.
Patient Preference Tool (PPT) (Mazur and Hickam, 1997)	USA	To evaluate patients' preferred role for accepting or rejecting invasive medical treatments.	A written structured interview	Patients at a university medical centre (n=467)	Not reported	Patients were given definitions of invasive medical interventions, then asked to participate in structured interviews and answer four questions about whether they understood the given definitions, if they would like to have risk disclosure, information about adverse outcomes and selecting an answer that demonstrated their preferred decision after having knowledge.
Role and Information Preferences (RIP) (Beisecker and Beisecker, 1990)	USA	To evaluate patients' desires for decisional roles and information	Patient self-administered questionnaire	Heterogeneous sample of rehabilitation medicine outpatients (age 17-85 years) (n=106)	Not described	Two separate scales with parallel items. **Information scale**: 13 items with statements about types of clinical information, such as problems and benefits of certain treatments, risk of diagnostic tests and treatment alternatives. A 5-point Likert scale from 1 (not at all important) to 5 (very important). **Decisional role scale:** The main question is who do you think should make the decision? Statements on drug prescriptions and alternatives of medical treatments were involved.
Decisional Conflict Scale (DCS) (O'conner, 1995)	Canada	1. To quantify patients' uncertainty in making health-related decisions 2. Main aim of this scale was to help patients to elicit preferences and support them in selecting the most appropriate treatment choice	Self-reported administration or over phone	Influenza immunization & breast cancer screening (n=909)	Based on decisional conflict construct, a panel of experts in field of decision-making and repeated testing	- It looks at patients' perceptions of difficulties, clarity, knowledge, satisfaction and choices available when making decisions. - The scale includes 16 items on three subscales: decision uncertainty, factors contributing to uncertainty and perceived effective decision making. Higher score reflects greater decisional conflict. It is available in English and other European languages in addition to a low literacy version reduced to 10 items.

Table 3 cont.: Descriptions of instruments developed and tested to examine patient involvement in decision making and information provision

Instrument Author/ Year of Publication	Country	Aim	Original method of administration	Original study setting and study population	Approach to item development and selection	Description of the items
Decision Attitude Scale (DAS) (Sainfort and Booske, 2000)	USA	To evaluate satisfaction with quality of a decision after it has been made	Patient self-administered measure.	State employees for their choice of health plan (n= 197)	Review of models for decision making and other relevant scales. A computerized system was specifically designed to collect data for this study. Four alternative health scenarios were provided. Individuals were provided with little information then with additional information and asked to indicate their choices and attitudes towards their health plan.	A scale of nine statements represents dimensions which evaluate feelings, behaviours and attitudes towards choices and decision process. Subscales were satisfaction with a choice, adequacy and usability of information provided. Response mode is a five-point Likert scale from 1 'strongly disagree' to 5 'strongly agree'.
Observing patient involvement Scale OPTION (Elwyn et al., 2003)	UK	To examine physicians' behaviour regarding patient involvement	Rating observation scale	Primary care settings. General practitioners (n=21)	Based on relevant literature and series of previous studies by authors to identify SDM competences observed during medical consultations	Composed of twelve items that reflect the competences of SDM. Raters indicate the presences or absence of each behaviour and rate it from 0 to 3.
Dyadic OPTION	UK	To examine perceived patient involvement in the medical consultation	Patient self-administered measure	Medical students acting as patients (n=36)	Adapted from the OPTION scale	Same contents as OPTION scale. Two versions were developed, for patients and clinicians.

APPENDIX 4.2

A Table reporting psychometric proprieties of instruments reviewed in chapter three

Table: Reported psychometric proprieties of instruments reviewed in chapter three

The instrument	Reported Validity Assessments	Reported Reliability Assessments
Autonomy Preference Index **(API)**	**Concurrent validity** for the DM Scale: Correlation with an empirically related global item appended to the instrument. (r=0.54; p<0.0001) **Criterion validity** for the DM Scale: Tested by administering DM scale to a selected population of diabetic patients. Mean scores of these patients were compared with scores of our general study population. This population scored significantly higher (p<0.01) on the DM than did the general population	Test-retest reliability (two-week period) on a sample of 50 patients (not defined): unreliable items were deleted. The test-retest was calculated on the remaining items using the Pearson product-moment correlations. DM: 0.84 and 0.83 for the information seeking
Krantz Health Opinion	**Construct validity**: Total score correlated weakly with 'health locus of control (r=.31), subscales correlated poorly. Also found very poorly correlated with the social desirability scale. Discriminate validity: discriminated in the use of clinic facilities (r=-0.28) and between a medical group of high self-care and general student population (t=2.69; p<0.5).	Internal consistency; total scale: Kuder Richardson 0.77, behaviour subscale 0.74 and information 0.76. Test-retest reliability; total scale: 0.74, behaviour subscale 0.71 and information 0.59.
Decisional Conflict Scale	**Construct validity**: discriminated between groups who accepted, rejected or delayed decisions (p< 0.0002). Inversely correlated to the knowledge scale: Pearson r=-0.16, p<0.05).	Internal consistency: Cronbach's α = 0.78. Test-retest reliability: Pearson r= 0.81.
Rochester Participatory Decision-Making Scale	**Construct validity**: correlated with standardized patient and real patient measures of constructs that related to DM. Also correlated with the measure of physician-patient interaction.	Test-retest reliability Intraclass correlation coefficient (ICC): 0.72. Reliability of the physician style using the Spearman-Brown prophecy formula: 0.053.
Shared Decision Making Questionnaire (SDM-Q)	**Construct validity**: moderately correlated with the subscale ''doctor facilitation'' (r = 0.32; a = 0.87) and weak correlations with ''patient information'' (r = 0.29; α = 0.83).	Internal consistency: Cronbach's α = 0.77.
The 9-item Shared Decision Making Questionnaire (SDM-Q-9)	**Face validity**: 80% of the involved sample reported a good acceptance. **Construct validity**: Item discriminations were performed. Corrected item-total correlations were ranged from 0.690 to 0.845.	Internal consistency: Cronbach's α = 0.9.

Table (cont.): Reported psychometric proprieties of instruments reviewed in chapter three

The Instrument	Reported Validity Assessments	Reported Reliability Assessments
The Satisfaction with Decision Scale (SWD)	Construct validity: weak correlations with education (r=0.22), knowledge of Menopause (r=0.21) and satisfaction with provider (r=0.23). Correlated Moderately with decisional conflict scale (r=0.54), perceived knowledge of Menopause (r=048) and confidence in decision (r=64).	Internal consistency: Cronbach's α = 0.87.
Patients' Perceived Involvement in Care Scale (PICS)	Construct Validity: Factor analysis; discriminated by gender: significantly correlates with health care satisfaction and pain-related communication barriers (Simon et al., 2007)	Internal consistency: Cronbach's α = 0.78.
The Desire for Involvement Questionnaire (DIQ)	Construct validity: moderately with the API (r=0.45) and weakly with the behavioural scale of the health opinion survey (r=.34).	Internal consistency: Cronbach's α = 0.87.
Patient Preference for Control	Construct Validity: Factor analysis; discriminated by scenarios): differences by age, income and education.	Internal consistency: Cronbach's α = 0.81.
Role and Information Preferences	Construct Validity: Factor analysis; discriminated throughout by a comparison between information seeking and decision making that revealed no correlation.	Test-retest reliability (ICC): 0.83-0.84 Internal consistency: Cronbach's α = 0.82.
EORTC questionnaire	Construct Validity: Factor analysis; discriminated by gender, age, levels of anxiety and depression and level of education throughout a longitudinal study with divers and wide sample of cancer patients from different European countries. Confirmed divergent validity: Weakly correlated with EORTC QLQ-C30 scales (r=0.3)	Internal consistency total score: Cronbach's α = 0.90. Test-retest (ICC): 0.70.
Preferences for Information	Not reported.	Not reported.
Control Preference Control	Construct Validity: reported based on a context of grounded theory.	reported to be adequately met criterion of Coombs measure of ordinal data reliability (58-66%) (Simon et al., 2007).
Participatory decision-making style	Construct Validity: Moderate correlations were established between the three questions to other questions in patients, and physicians' questionnaires and clinician background questionnaire (r= 0.45; p<0.001).	Interclass correlations of physicians = 0.62.

APPENDIX 4.3

A copy of the Control Preference Scale

The Control Preference Scale (Degner, et al 1997)

Figure 1 *The Control Preferences Card Set*

Active Role

A. I prefer to make the decision about which treatment I will receive.

B. I prefer to make the final decision about my treatment after seriously considering my doctor's opinion.

Passive Role

E. I prefer to leave all decisions regarding treatment to my doctor.

D. I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.

Collaborative Role

C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

APPENDIX 4.4

Patient Low Back Pain baseline information

- **Is this is your first course of physiotherapy because of low back pain?**

  - ❑ Yes
  - ❑ No

  If "No", how many previous physiotherapy courses have you had?

  - ❑ 1
  - ❑ 2-3
  - ❑ > 3

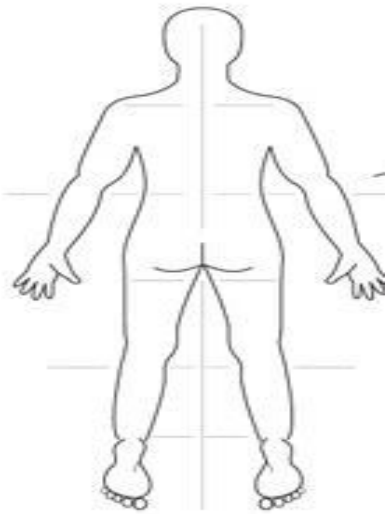
- **Pain Intensity**

  Please identify your pain level (now, before starting the physiotherapy treatment programme) as shown below, where 0 indicate no pain and 10 indicate the worst pain you may have due to your back problem.

0	1	2	3	4	5	6	7	8	9	10
No pain										Worst pain

- **Pain Location**

  On this chart, please identify the location of your low back pain, before you started the physiotherapy treatment programme.



The Hospital Anxiety and Depression (HAD) Scale

Doctors are aware that emotions play an important part in most illness. If your doctor knows about these things, he will be able to help you more.

This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

Tick only one box in each section

I feel tense or "wound up" :

Most of the time …….	
A lot of the time ……..	
Time to time, Occasionally……..	
Not at all ……..	

I feel as if I am slowed down:

Nearly all the time …….	
Very often ……..	
Sometimes …….	
Not at all ……	

I still enjoy the things I used to enjoy:

Definitely as much	
Not quite so much	
Only a little	
Hardly at all	

I get a sort of frightened feeling like butterflies in the stomach:

Not at all ……..	
Occasionally ……..	
Quite often ……..	
Very often ……	

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly …..	
Yes, but not too badly …….	
A little, but it doesn't worry me ……	
Not at all ……..	

I have lost interest in my appearance:

Very much indeed ……	
Quite a lot ……..	
Not very much ……..	
Not at all ……	

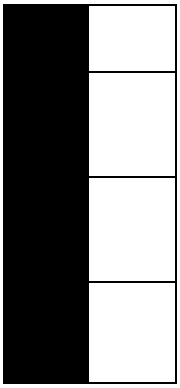
I can laugh and see the funny side of things

As much as I always could ……..

Not quite so much now……..

Definitely not so much …….

Not at all ……



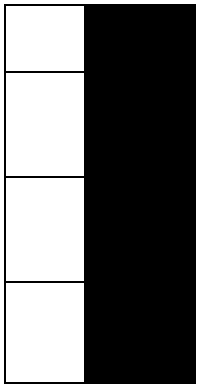
I feel restless, as if I have to be on the move

Very much indeed ……..

Quite a lot ……

Not very much …….

Not at all ……



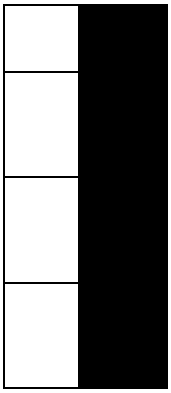
Worrying thoughts go through my mind:

A great deal of the time ……

A lot of the time ……

Time to time, but not too often ……..

Only occasionally……. ……



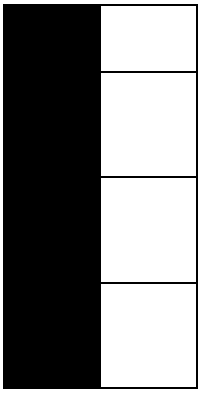
I look forward with enjoyment to things:

As much as I ever did ……..……

Rather less than I used to … ……

Definitely less than I used to ……

Hardly at all ……



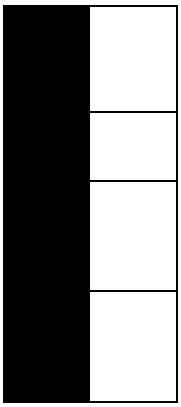
I feel cheerful:

Not at all ……. …….

Not often …….

Sometimes ……. …….

Most of the time ……. ……



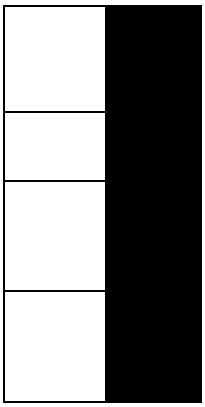
I get sudden feelings of a panic:

Very often indeed ……. ……

Quite often ……

Not very often ……

Not at all …….. ……



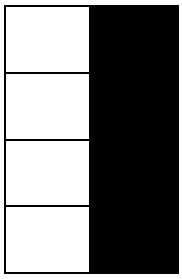
I can sit at ease and feel relaxed:

Definitely ……

Usually ……..

Not often ……

Not at all ……..



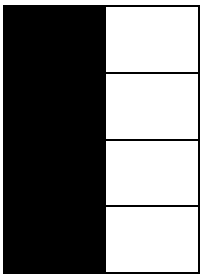
I enjoy a good book or radio or TV programmes

Often ……

Sometimes ……

Not Often ……..

Very seldom ……



The Modified Ronald Morris (Questionnaire):

When your back or leg hurts, you may find it difficult to do some of the things you normally do. This list contains some sentences people have used to describe themselves when they have back pain or sciatica. When you read them, you may find that some stand out because they describe you today. As you read this list, think of yourself today. When you read the sentence that describes you today, put a tick in the **Yes box** ☐. If the sentence does not describe you, tick the **No box** .☐

1. I stay at home most of the time because of my back problem or leg pain (sciatica).

   Yes ☐ **No** ☐

2. I change position frequently to make my back problem or leg comfortable.

   Yes ☐ **No** ☐

3. I walk more slowly than usual because of my back problem or leg pain (sciatica).

   Yes ☐ **No** ☐

4. Because of my back problem, I am not doing any of the jobs that I usually do.

   Yes ☐ **No** ☐

5. Because of my back problem, I use a handrail to get upstairs.

   Yes ☐ **No** ☐

6. Because of my back problem, I have to hold onto something to get out of an easy chair.

   Yes ☐ **No** ☐

7. I get dressed more slowly than usual because of my back problem or leg pain.

   Yes ☐ **No** ☐

8. I stand for only short periods of time because of my back problem or leg pain.

   ☐ ☐

Yes **No**

9. Because of my back problem, I try not to bend or kneel down.

Yes ☐ **No** ☐

10. I find it difficult to turn over in bed because of my back problem or leg pain (sciatica).

Yes ☐ **No** ☐

11. My back or leg is painful almost all of the time.

Yes ☐ **No** ☐

12. I walk only short distances because of my back problem or leg pain.

Yes ☐ **No** ☐

13. I sleep less because of my back or leg pain (sciatica).

Yes ☐ **No** ☐

14. Because of my back or leg pain, I avoid heavy jobs around the house or at work.

Yes ☐ **No** ☐

15. Because of my back or leg pain, I am more irritable and bad-tempered with people.

Yes ☐ **No** ☐

16. I go upstairs more slowly than usual because of my back problem.

Yes ☐ **No** ☐

17. Because of my back problem, I stay in bed most of the time.

Yes ☐ **No** ☐

18. My sexual activity is decreased because of my back problem.

Yes ☐ **No** ☐

19. I keep rubbing or holding areas of my body that hurt or are uncomfortable.

Yes ☐ **No** ☐

20. Because of my back problem, I am doing less daily work than I would usually do.

Yes ☐ **No** ☐

21. I often express concern to other people over what might be happening to my health.

Yes ☐ **No** ☐

APPENDIX 4.5

Items removed from the Autonomy Preference Index

Table: Items removed from the API

- If a chest X-ray should be taken
- If you should try taking cough syrup
- When the next visit to check your blood pressure should be
- Whether laboratory tests should be done
- Whether you should be treated with medication or diet
- Whether a specialist in high blood pressure might be helpful
- How often the nurses should wake you up to check your temperature and blood pressure
- Whether you may have visitors aside from your immediate family
- Whether it is necessary for you to give up an activity which you really enjoy
- When you are well, how much do you want to participate in the medical decisions that are made?
- When you get sick, how much do you want to participate in the medical decisions that are made?
- When you are seriously ill, how much do you want to participate in the medical decisions that are made?
- Considering all the ways your health affects you, how well are you doing?
- Thinking about the past three months, how much of the time has your health kept you from doing the things that you should be doing?
- During the past three months, how much has your health worried or concerned you?
- Are you currently taking medications?
- The care I have received from doctors in the last few years is just about perfect.
- Most people receive medical care that could be better.
- The doctor took charge.
- Patients should not make decisions about a problem which might be life threatening.

APPENDIX 4.6

New items added to the Autonomy Preference Index

Table: New items added to patient questionnaire

General perception of preferences for decision making

- I should normally participate with my physiotherapists in making decisions about my LBP management

Situation-based preferences as to who should make decisions

- What type of treatment I should receive in the physiotherapy department
- Whether I should do a home management programme following my visit to the physiotherapy department
- How frequently I should be seen by my physiotherapist
- How much supervision I need during physiotherapy treatment sessions
- When a more senior physiotherapist should be consulted about my LBP management
- Whether I need to be referred back to my treating physician
- When I should be discharged from physiotherapy services
- Whether my views should be taken into account in the discharge plan

Satisfaction with decisions made and information gathered

- I was satisfied with the information I was given about my back pain

Perception of the recent Personal Experience with Physiotherapy Program

- Do you think that the degree of your pain affected how much you wanted to be involved in the decisions made by your physiotherapist?
- My physiotherapist encouraged decisions about the management of my LBP to be made by: me alone, mostly me, me and my physiotherapist equally, mostly by my physiotherapist, my physiotherapist alone
- Decisions about the management of my LBP were made by: me alone, mostly me, me and my physiotherapist equally, mostly by my physiotherapist, my physiotherapist alone
- The physiotherapist encouraged me to gather as much information I wanted from her/him about my LBP and its management
- **I gathered information from the physiotherapist about my LBP**
- Please indicate below what information you were given during your last course of treatment (choose one or more):
  - back pain in general: types, causes, medical & surgical management, and any complications
  - normal spine motion and body posture
  - pain level, effects & management
  - self-management programmes: positions & movements
  - preventive management positions & movements
  - common physiotherapy management for LBP
  - others (Please specify)

APPENDIX 4.7

Item wording of patients' and physiotherapists' questionnaires

Table: Patient and physiotherapist questionnaires after development

Section I/A: General perceptions of preferences for decision making		
	PATIENT VERSION	**PHYSIOTHERAPIST VERSION**
1	The important management decisions should be made by the physiotherapist, not me	The important management decisions should be made by the physiotherapist, not patients
2	I should go along with the physiotherapist's advice even if I disagree with it	Patients should go along with the physiotherapist's advice even if they disagree with it
3	Patients in physiotherapy departments should not make decisions about their own physiotherapy care	Patients in physiotherapy departments should not make decisions about their own physiotherapy care
4	I should decide how frequently I should be seen by my physiotherapist	Patients should decide how frequently they should be seen by their physiotherapists
5	I should decide whether I need a follow-up physiotherapy appointment	Patients should decide whether they need a follow-up physiotherapy appointment
6	I should feel free to make decisions about my physiotherapy management	Patients should feel free to make decisions about their physiotherapy management
7	I should normally participate with my physiotherapists in making decisions about my LBP management	Patients should normally participate with physiotherapists in making decisions about their LBP management
Section I/B: Situation-based preferences as to who should make decisions		
8	Whether I should change/adjust my routine daily activities	Whether patients should change/adjust their routine daily activities
9	When I am ready to carry out my routine daily activities	When patients are ready to carry out their routine daily activities
10	What type of treatment I should receive in the physiotherapy department	What type of treatment patients should receive in the physiotherapy department
11	Whether I should do a home management program following my visit to the physiotherapy department	Whether patients should do a home management program following their visits to the physiotherapy department
12	How frequently I should be seen by my physiotherapist	How frequently patients should be seen by their physiotherapists
13	How much supervision I need during physiotherapy treatment sessions	How much supervision patients need during physiotherapy treatment sessions
14	When a more senior physiotherapist should be consulted about my LBP management	When a more senior physiotherapist should be consulted about a patient's LBP management
15	Whether I need to be referred back to my treating physician	Whether patients need to be referred back to their treating physician
16	When I should be discharged from physiotherapy services	When patients should be discharged from physiotherapy services
17	Whether my views should be taken into account in the discharge plan	Whether patient's views should be taken into account in the discharge plan
18	**In general, which statement *best* describes your own attitude in making-decisions about physiotherapy management for your LBP? Please tick the option that most reflects your view (Please choose only one)** *I prefer to make the decision about which treatment I will receive.	**In general, which statement *best* describes your own attitude towards physiotherapy care? Please tick the option that most reflects your view (Please choose only one)** *I prefer to make the decisions about which treatment I will give

	*I prefer to make the final decision about my treatment after seriously considering my physiotherapist's opinion. *I prefer that my physiotherapist and I share the responsibility for deciding which treatment is best for me. *I prefer that my physiotherapist makes the final decision about which treatment will be used, but after seriously considering my opinion. *I prefer to leave all decisions regarding treatment to my physiotherapist	*I prefer to make the final decision about which treatment will be used, but after seriously considering the patient's opinion *I prefer that patients and I share the responsibility for deciding which treatment is best for them *I prefer patients to make the final decision about their treatment after seriously considering my opinion *I prefer to leave all decisions regarding treatment to patients
	Section II: Preferences for information provision	
19	I should be given information only when I ask for it.	Patients should be given information only when they ask for it
20	Informing patients is an essential part of any physiotherapy management for LBP	Patients should have a good understanding of their LBP
21	I should have a good understanding of my LBP	Informing patients is an essential part of any physiotherapy management for LBP
22	If the level of my back pain changes, I should be given more information about what is happening to my back	If the level of patient' s back pain changes, they should be given more information about what is happening to their back
23	If the news about my back pain is bad, I should be fully informed	If the news about patient's back pain is bad, they should be fully informed
24	Physiotherapists should explain the purpose of any physiotherapy clinical examinations that they use when assessing of my LBP	I should explain the purpose of any physiotherapy clinical examinations that I use when assessing of patient's LBP
25	When there is more than one method to treat my LBP, I should be informed about each one	When there is more than one method to treat patient's LBP, they should be informed about each one
26	It is important for me to know all possible adverse effects of any physiotherapy interventions used to manage my back pain	It is important for patients to know all the possible adverse effects of any physiotherapy interventions used to manage their back pain
	Section III: Perception of recent personal experience with physiotherapy care	
27	In your most recent experience with the physiotherapist, how much did you participate in the decision-making process?	In your most recent experience with the patient, how much did she/he participate in the decision-making process?
28	Do you think that the degree of your pain affect how much you wanted to be involved in the decisions made by your physiotherapist?	Do you think that the severity of patient's pain affected how much she/he wanted to be involved in the decisions made by you?
29	My physiotherapist encouraged decisions about the management of my LBP to be made by: me alone, mostly me, me & my physiotherapist equally, mostly by my physiotherapist, my physiotherapist alone	I encouraged decisions about the management of patient's LBP to be made by: me alone, mostly me, me & the patient equally, mostly by the patient, the patient alone
30	Decisions about the management of my LBP were made by: me alone, mostly me, me and my physiotherapist equally, mostly by my physiotherapist, my physiotherapist alone	Decisions about the management of a patient's LBP were made by: me alone, mostly me, me and the patient equally, mostly by the patient, the patient alone
31	The physiotherapist encouraged me to gather as much information as I wanted from her/him about my LBP and its management.	The patient gathered information from me about her/his LBP
32	I gathered information from the physiotherapist about my LBP **Please indicate below what information you were given during your last course of treatment (choose one or more):** *Back pain in general: types, causes, medical & surgical management, and any complications *Normal spine motion and body posture *Pain level, effects & management *Your Self-management programmes: Positions & movements *Preventive management positions & movements *Common physiotherapy management for LBP *Others (Please specify)	**Please indicate below what information you gave your last patient (choose one or more):** *Back pain in general: types, causes, medical & surgical management, and any complications *Spine biomechanics and healthy posture *Pain behaviour & management *Self-management programmes *Preventive management strategies *Common physiotherapy management for LBP *Others (Please specify)

APPENDIX 4.8

Patient questionnaire – Key labels to describe preferences for decisional roles and information desires

Table : Patient questionnaire – Key labels to describe preferences for decisional roles and information desires

Question number	Questionnaire items	Preferences for decisional role
Preferences for patient participation as a general perception		
1	The important management decisions should be made by the physiotherapist, not patients	**Passive**
2	Patients should decide how frequently they should be seen by their physiotherapists	**Active**
3	Patients in physiotherapy departments should not make decisions about their own physiotherapy care	**Passive**
4	Patients should decide whether they need a follow-up physiotherapy appointment	**Active**
5	Patients should go along with the physiotherapist's advice even if they disagree with it	**Passive**
6	Patients should feel free to make decisions about their physiotherapy management	**Active**
7	Patients' views should be taken into account in the discharge plan	**Active**
8	Patients should normally participate with their physiotherapists in making decisions about my LBP management	**Active**
Types of Decisional Roles		
Patients alone or mostly by patients = Predominantly by patients		**Active**
Patients and physiotherapists equally		**Sharing / collaborative**
Physiotherapists alone or mostly by physiotherapists = Predominantly by physiotherapists		**Passive**
Preferences for patient participation in specific clinical situations		
9	Whether patients should change/adjust their routine daily activities	
10	When patients are ready to carry out their routine daily activities	
11	What type of treatment patients should receive in the physiotherapy department	
12	Whether patients should do a home management programme following their visits to the physiotherapy department	
13	How frequently patients should be seen by their physiotherapist	
14	How much supervision patients need during physiotherapy treatment sessions	
15	When a more senior physiotherapist should be consulted about patients' LBP management	
16	Whether patients need to be referred back to their treating physician	
17	When patients should be discharged from physiotherapy services	
18	In general, which statement best describes your own attitude in making-decisions about physiotherapy management for patients' LBP?	
Desire for Information		
19	Patients should be given information only when they ask for it	**Weak Desire**
20	Informing patients is an essential part of any physiotherapy management for LBP	**Strong Desire**
21	Patients should have a good understanding of their LBP	**Strong Desire**

22	If the level of patients' back pain changes, patients should be given more information about what is happening to their back	**Strong Desire**
23	If the news about patients' back pain is bad, patients should be fully informed	**Strong Desire**
24	Physiotherapists should explain the purpose of any physiotherapy clinical examinations that they use when assessing of patients' LBP	**Strong Desire**
25	When there is more than one method to treat patients' LBP, patients should be informed about each one	**Strong Desire**
	Table (cont.): Patient questionnaire – Key labels to describe preferences for decisional roles and information desires	
	Desire for Information	
26	It is important for patients to know all the possible adverse effects of any physiotherapy interventions used to manage their back pain	**Strong Desire**
	Experienced Preferences	
27	How much did patients participate in the decision-making process?	Full, partial or no participation
28	How much information did patients gather from their physiotherapists about their LBP?	Full, partial or no participation
29	Do you think that the severity of patients' pain affected how much patients wanted to be involved in the decisions made?	Full, partial or no participation
30	How much did physiotherapists encourage patients to participate in making decisions about the management of their LBP?	Full, partial or no participation
31	How much did physiotherapists encourage patients to gather information patients wanted from her/him about patients' LBP and its management?	Full, partial or no participation
32	Do you think your decisions about patient's LBP affect their adherence to the plan of management?	Full, partial or no participation

APPENDIX 4.9

The final draft of the patients' questionnaire

Patients' preferences for participation in decision making and information provision

Kindly note that this page will be removed from this questionnaire immediately after we link it with the Part I questionnaires

This page will be completely destroyed

PATIENT'S NAME:

Decision Making in the Physiotherapy Management of Low Back Pain: Patient's Preferences

Questionnaire Cover Sheet

Dear patient

Thank you for your interest in participating in this survey.

This questionnaire will ask you about how you like to reach decisions about your care when receiving treatment for your low back pain (LBP) from your physiotherapist. In addition, we are interested in your views about the information you like to gather.

The questionnaire should take no more than 25 minutes to complete. Before filling it in, please read the "General Information Sheet for Participants". Your answers will remain confidential to the research team and they will not become part of your medical records.

Please follow the instructions for each section carefully and do exactly as required for each question.

If you require any further information please do not hesitate to contact me using the contact information below.

We hope you find it interesting.

Thank you for your participation.

Wafa M. Al-Khatrawi

e-mail: wafa.al-khatrawi@kcl.ac.uk

Mobile: 0569817943

1. Patient's Socio-demographic Characteristics

First, we would like to ask you some questions about yourself.

- **Please put a cross in the BOX X which most closely relates to your personal data:**

- **Age** ❑ 18 - 24 ❑ 25 - 34 ❑ 35 - 44 ❑ 45 - 54 ❑ > 54	- **Gender** ❑ Female ❑ Male
- **Educational Level** ❑ Primary ❑ Intermediate/secondary ❑ College/University ❑ Postgraduate ❑ Other (specify)	- **Occupational Status** ❑ Unemployed ❑ Manual work /skilled job ❑ Housewife ❑ Professional ❑ Student ❑ Retired ❑ Other (specify)
- **Your Current Housing** ❑ Villa ❑ Semi-villa/flat ❑ Mud/traditional house	

SECTION I: Making Decisions

In this section we would like to ask you about how you like to make decisions about the management of your low back pain (LBP) when attending for physiotherapy. There are no right or wrong answers. We are only interested in your opinion.

A. **Please tick the option that most closely reflects your view regarding how strongly you agree or disagree with each statement.** **Please answer all questions:**	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. The important management decisions should be made by the physiotherapist, not me.					
2. I should decide how frequently I should be seen by my physiotherapist.					
3. Patients in physiotherapy departments should not make decisions about their own physiotherapy care.					
4. I should decide whether I need a follow-up physiotherapy appointment.					
5. I should go along with the physiotherapist's advice even if I disagree with it.					
6. I should feel free to make decisions about my physiotherapy management.					
7. My views should be taken into account in the discharge plan.					
8. I should normally participate with my physiotherapists in making decisions about my LBP management.					

B. Please tick the option that most closely indicates your general views regarding <u>whether you or your physiotherapist should take charge in making the following decisions</u> about management of your LBP. Please answer all questions:

Who should take charge of making decisions about:	You alone	Mostly you	The physiotherapist and you equally	Mostly the physiotherapist	The physiotherapist alone
9. whether I should change/adjust my routine daily activities.					
10. when I am ready to carry out my routine daily activities.					
11. what type of treatment I should receive in the physiotherapy department.					
12. whether I should follow a home management programme following my visit to the physiotherapy department.					
13. how frequently I should be seen by my physiotherapist.					
14. how much supervision I need during physiotherapy treatment sessions.					
15. when a more senior physiotherapist should be consulted about my LBP management.					
16. whether I need to be referred back to my treating physician.					
17. when I should be discharged from physiotherapy services.					

18. In general, which statement <u>best</u> describes your overarching preference for patient participation in decision making?

Please tick the option that most closely reflects your view (Please choose only one)

- ☐ I prefer to make the decision about which treatment I will receive.
- ☐ I prefer to make the final decision about my treatment **after seriously considering my physiotherapist's opinion.**
- ☐ I prefer my physiotherapist to share with me the responsibility for deciding which treatment is best for me.
- ☐ I prefer my physiotherapist to make the final decision about which treatment will be used, **but after seriously considering my opinion.**
- ☐ I prefer to leave all decisions regarding my treatment to my physiotherapist.

SECTION II: Information

In this section we would like you to think about the information you want to know about your LBP. There are no right or wrong answers. We are only interested in your opinion.

Please tick the option that most closely reflects your view regarding how strongly you agree or disagree with each statement. **Please answer all questions:**	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
19. I should be given information only when I ask for it.					
20. Informing patients is an essential part of any physiotherapy management for LBP.					
21. I should have a good understanding of my LBP.					
22. If the level of my back pain changes, I should be given more information about what is happening to my back.					
23. If the news about my back pain is bad, I should be fully informed.					
24. Physiotherapists should explain the purpose of any physiotherapy clinical examinations that they use when assessing my LBP.					
25. When there is more than one method to treat my LBP, I should be informed about each one.					
26. It is important for me to know all the possible adverse effects of any physiotherapy interventions used to manage my back pain.					

Please note: This questionnaire has a second part for you to complete at the end of your treatment session, if you decide to do so.

Part 2

Patient preferences for participation in decision making and information provision

Please write your name below

Kindly note that this page will be removed from this questionnaire immediately after we link it with Part I of this questionnaire

This page will be completely destroyed

PATIENT'S NAME:

SECTION III: Your recent course of physiotherapy care

In this section we would like you describe how you and your physiotherapist made decisions during your last course of treatment. There are no right or wrong answers. We are only interested in your opinion.

A. Please tick the option that most closely reflects your answer to each of the following questions regarding your most recent experience with the physiotherapist. **Please answer all questions.**	**Not at all**	**A little**	**A fair amount**	**A lot**	**A great deal**
27. How much did you participate in the decision-making process?					
28. How much information did you gather from your physiotherapist about your LBP?					
29. Do you think that the severity of your pain affected how much you wanted to be involved in the decisions made?					
30. How much did your physiotherapist **encourage** you to participate in making decisions about the management of your LBP?					
31. How much did your physiotherapist **encourage** you to gather information you wanted from her/him about you LBP and its management?					

32. Please indicate below what information you were given during your last course of treatment (choose all the types that you received).

I received information about:

- ☐ Back pain in general: types, causes, medical & surgical management, and any complications
- ☐ Normal spine motion and body posture
- ☐ Pain level, effects & management
- ☐ Your self-management programmes: Positions & movements
- ☐ Preventive management, positions & movements
- ☐ Common physiotherapy management for LBP
- ☐ Others (Please specify) _____
- ☐ No information was given

SECTION IV: Level of Satisfaction

In this section we would like to know how satisfied you are with the way you and your physiotherapist made decisions, and the information you were given during the last course of physiotherapy treatment for your LBP. There are no right or wrong answers. We are only interested in your opinion.

Please tick the option that most closely reflects your view regarding how strongly you agree or disagree with each statement.	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
33. I am very satisfied with the physiotherapy I received.					
34. There are things about the physiotherapy I received that could have been better.					
35. I was satisfied with how decisions were made.					
36. I was satisfied with the information I was given about my back pain.					

******** THIS IS THE END OF THE QUESTIONNAIRE *********

******* THANK YOU FOR YOUR PARTICIPATION *******

APPENDIX 4.10

The final draft of the Physiotherapists' questionnaire

Physiotherapists' preferences for participation in decision making and information provision

Dear Physiotherapist

Thank you for your interest in participating in this survey.

This questionnaire will ask you about how you like to make decisions when treating patients with low back pain (LBP). In addition, we are interested in your views about the information they should have.

The questionnaire should take no more than 25 minutes to complete. Before filling it in, please read the "General Information Sheet for Physiotherapists". Your answers will remain confidential to the research team and they will not become part of any other records.

Please follow the instructions for each section carefully and do exactly as required for each question.

If you require any further information, please do not hesitate to contact me using the information below.

We hope you find it interesting.

Thank you for your participation.

Wafa M. Al-Khatrawi

e-mail: wafa.al-khatrawi@kcl.ac.uk

Mobile: 0531639118

1. Physiotherapist's Socio-demographic Characteristics

First, we would like to ask you some questions about yourself.

- **Please put a cross in the BOX X which most closely relates to you.**

- **Age** ❑ 24-30 ❑ 31-35 ❑ 36-40 ❑ 41-45 ❑ > 45	- **Gender** ❑ Female ❑ Male
- **Years since Graduation** ❑ < 5 ❑ 5-7 ❑ 7-10 ❑ 10-15 ❑ > 15	- **Professional Qualifications** ❑ Baccalaureate ❑ Professional Masters ❑ Professional Doctorate ❑ Other/specify
- **Work Position** ❑ Staff Therapist ❑ Senior Therapist ❑ Specialist/Clinical Supervisor ❑ Other/specify ----------	- **Type of Hospital** ❑ Military ❑ Civilian (Ministry of Health) ❑ University ❑ Private ❑ Other/specify ----------
- **Average number of new patients with LBP/week** ❑ < 3 ❑ 3-5 ❑ > 5	- **Type/s of commonly seen LBP (select one or more)** ❑ Acute ❑ Sub-acute ❑ Chronic ❑ LBP + nerve root involvement ❑ LBP + Red-flag condition/s.

SECTION I: Making Decisions

In this section we would like to ask you about how you generally make decisions about the physiotherapy assessment and management of patients with low back pain (LBP). Please tick the box that most closely reflects your view. There are no right or wrong answers. We are only interested in your opinion.

B. Please tick the option that most closely reflects your view regarding how strongly you agree or disagree with each statement. Please answer all questions	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. The important management decisions should be made by the physiotherapist, not the patient					
2. Patients should decide how frequently they should be seen by their physiotherapists					
3. Patients in physiotherapy departments should not make decisions about their own physiotherapy care					
4. Patients should decide whether they need a follow-up physiotherapy appointment					
5. Patients should go along with the physiotherapist's advice even if they disagree with it					
6. Patients should feel free to make decisions about their own physiotherapy management					
7. Patient's views should be taken into account in the discharge plan					
8. Patients should normally participate with physiotherapists in making decisions about the management of their LBP					

C. **Please tick the option that most reflects your general views about who should make the decisions in the management of patients with LBP. Please answer all questions**

Who should make decision about:	**You alone**	**Mostly you**	**The patient and you equally**	**Mostly the patient**	**The patient alone**
9. whether patients should change/adjust their routine daily activities					
10. when patients are ready to carry out their routine daily activities					
11. what type of treatment patients should receive in the physiotherapy department					
12. whether patients should follow a home management programme following their visits to the physiotherapy department					
13. how frequently patients should be seen by their physiotherapists					
14. how much supervision patients need during physiotherapy treatment sessions					
15. when a more senior physiotherapist should be consulted about the patient's LBP management					
16. whether patients need to be referred back to their treating physician					
17. when patients should be discharged from physiotherapy services					

18. In general, which statement <u>best</u> describes your overarching preference for patient participation in decision making?

Please tick the option that most closely reflects your view (Please choose only one)

- ☐ I prefer to make the decisions about which treatment I will give.
- ☐ I prefer to make the final decision about which treatment will be used, **but after seriously considering the patient's opinion.**
- ☐ I prefer to share with patients the responsibility for deciding which treatment is best for them.
- ☐ I prefer patients to make the final decision about their treatment **after seriously considering my opinion.**
- ☐ I prefer to leave all decisions regarding treatment to patients.

SECTION II: Information

In this section we would like you to think about the information you want patients to gather about their LBP. There are no right or wrong answers. We are only interested in your opinion.

Please tick the option that most closely reflects your view regarding how strongly you agree or disagree with each statement. **Please answer all questions**	**Strongly Disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
19. Patients should be given information only when they ask for it					
20. Patients should have a good understanding of their LBP					
21. Informing patients is an essential part of any physiotherapy management of LBP					
22. If the level of patient s' back pain changes, they should be given more information about what is happening to their back					
23. If the news about patients' back pain is bad, they should be fully informed					
24. I should explain the purpose of any physiotherapy clinical examinations that I use when assessing a patient's LBP					
25. When there is more than one method to treat patients' LBP, they should be informed about each one					
26. It is important for patients to know all the possible adverse effects of any physiotherapy interventions used to manage their back pain					

SECTION III: Your Recent Personal Experience

In this section we would like you to consider the last patient you had with low back pain. There are no right or wrong answers. We are only interested in your opinion.

Please tick the option that most closely reflects your answer to each of the following questions regarding your most recent experience with an LBP patient **Please answer all questions**	**Not at all**	**A little**	**A fair amount**	**A lot**	**A great deal**
27. How much did the patient participate in the decision-making process?					
28. How much information did you give to your patient about his/her LBP?					
29. Do you think the severity of patient's pain affected how much she/he wanted to be involved in the decisions made by you?					
30. How much did you encourage the patient to participate in making decisions about the management of her/his LBP?					
31. How much did you encourage the patient to gather information she/he wanted from you about her/his LBP and its management?					
32. Do you think your decisions about the patient's LBP affect his/her adherence to the plan of management?					

33. Please indicate below what information you gave your last patient (Choose all the types that you gave)
I gave information about:

- ☐ Back pain in general: types, causes, medical & surgical management, and any complications
- ☐ Spine biomechanics and healthy posture
- ☐ Pain behaviour & management
- ☐ Self-management programmes
- ☐ Preventive management strategies
- ☐ Common physiotherapy management for LBP
- ☐ Others (Please specify) _____
- ☐ No Information was given

34. In this most recent experience, which of the following factors do you think affected your attitude toward whether to involve the patient in making decisions about his/her back pain? (Choose one or more):

- ☐ Patient's low back pain condition; for example, the severity of pain, disability, …… etc.
- ☐ Patient's age
- ☐ Patient's education level
- ☐ Patient's social/cultural background
- ☐ Patient's behaviour and psychological wellbeing
- ☐ Patient's feedback about your treatment programme
- ☐ Others (please specify) ----------

THIS IS THE END OF THE QUESTIONNAIRE

THANK YOU FOR YOUR PARTICIPATION

APPENDIX 5.1

Study 1 and 2:

The ethical approval from the Research Ethics Committee at King's College London

Wafa Al-Khatrawi

King's College London

Guy's Campus

3.11 Shepherd's House

London SE1 1UL

3rd February 2009

Dear Wafa

BDM/08/09-28 Study of patient - physiotherapist congruence: preferences in making decisions about managing low back pain in Saudi Arabia

Thank you for sending in the amendments requested to the above project. I am pleased to inform you that these meet the requirements of the BDM RESC and therefore that full approval is now granted.

Please ensure that you follow all relevant guidance as laid out in the King's College London *Guidelines on Good Practice in Academic Research* (http://www.kcl.ac.uk/college/policyzone/attachments/good_practice_May_08_FINAL.pdf).

For your information ethical approval is granted until **3rd February 2010**. If you need approval beyond this point you will need to apply for an extension to approval at least two weeks prior to this explaining why the extension is needed, (please note however that a full re-application will not be necessary unless the protocol has changed). You should also note that if your approval is for one year, you will not be sent a reminder when it is due to lapse.

If you do not start the project within three months of this letter please contact the Research Ethics Office. Should you need to modify the project or request an extension to approval you

will need approval for this and should follow the guidance relating to modifying approved applications: http://www.kcl.ac.uk/research/ethics/applicants/modifications.html

Any unforeseen ethical problems arising during the course of the project should be reported to the approving committee/panel. In the event of an untoward event or an adverse reaction a full report must be made to the Chairman of the approving committee/review panel within one week of the incident.

Please would you also note that we may, for the purposes of audit, contact you from time to time to ascertain the status of your research.

If you have any query about any aspect of this ethical approval, please contact your panel/committee administrator in the first instance (http://www.kcl.ac.uk/research/ethics/contacts.html). We wish you every success with this work.

With best wishes
Yours sincerely

Riina Heinonen

Research Ethics Officer (Health)

BDM RESC

c.c. Professor Sheila Kitchen

APPENDIX 9.1

Study 4 and 5

King's College London Ethical Approval

Wafa Al-Khatrawi
King's College London
Guys Campus
3.11 Shepherd's House

London
SE1 1UL

11 August 2010

Dear Wafa Al-Khatrawi

BDM/09/10-87 Focus groups to investigate patients' and physiotherapists' views of making decisions and sharing information on managing lower back pain in Saudi Arabia

Thank you for sending in the amendments requested to the above project. I am pleased to inform you that these meet the requirements of the BDM RESC and therefore that full approval is now granted with the following proviso:

1. In your response to bullet point 5 V of our letter dated 26/07/10 we note your reluctance to state that there is a financial incentive for participation. However, at the same time, potential participants need to be fully informed prior to agreeing to participate of all aspects of participation. Therefore, please ensure you state on the Information Sheet that there will be a 'small gift' as compensation for participating. This wording should avoid the creation of false expectations from participants.

Please ensure that you follow all relevant guidance as laid out in the King's College London Guidelines on Good Practice in Academic Research (http://www.kcl.ac.uk/college/policyzone/attachments/good_practice_May_08_FINAL.pdf).

For your information ethical approval is granted until **11 August 2012**. If you need approval beyond this point you will need to apply for an extension to approval at least two weeks prior to this explaining why the extension is needed, (please note however that a full re-application will not be necessary unless the protocol has changed). You should also note that if your approval is for one year, you will not be sent a reminder when it is due to lapse.

If you do not start the project within three months of this letter please contact the Research Ethics Office. Should you need to modify the project or request an extension to approval you will need approval for this and should follow the guidance relating to modifying approved applications: http://www.kcl.ac.uk/research/ethics/applicants/modifications.html

Any unforeseen ethical problems arising during the course of the project should be reported to the approving committee/panel. In the event of an untoward event or an adverse reaction a full report must be made to the Chairman of the approving committee/review panel within one week of the incident.

Please would you also note that we may, for the purposes of audit, contact you from time to time to ascertain the status of your research.

If you have any query about any aspect of this ethical approval, please contact your panel/committee administrator in the first instance (http://www.kcl.ac.uk/research/ethics/contacts.html). We wish you every success with this work.

With best wishes

Yours sincerely

Jim Summers

Senior Research Ethics Officer

c.c. Dr Sheila Kitchen